The Barriers to Uptake of Diabetes Education (BUDiE) Study

Harris, Sophie Myra

Awarding institution:
King's College London

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PhD thesis

Diabetes Research Department,
Division of Diabetes and Nutritional Sciences,
King's College London

Sophie Harris
Student number: 1472870

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Supervisors:
Professor Stephanie Amiel
Dr Henrietta Mulnier

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1 Table of Contents

2 Table of Tables

3 Table of Figures

4 Abbreviations used in this thesis

Abbreviation	Phrase
A&E	Accident and Emergency
AHA	American Heart Association
BAPCR	British Association for Cardiovascular Prevention and Rehabilitation
BME	Black and Minority Ethnic
BTS	British Thoracic Society
CASP	Critical Appraisal Skills Programme
CIDS	Confidence in Diabetes Self-care scale
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
CONSORT	Consolidated Standards of Reporting Trials
CRN	Clinical Research Network
CSII	Continuous Sub-cutaneous Insulin Infusion
DAFNE	Dose Adjustment For Normal Eating
DAS	Diabetes Attitudes Score
DCCT	Diabetes Control and Complications Trial
DECS	Diabetes Eye Complication Screening
DESMOND	Diabetes Education and Self-Management for On-going and Newly Diagnosed
DM	Diabetes Mellitus
DNT	Diabetes Numeracy Test
DSN	Diabetes Specialist Nurse
FIIT	Flexible Intensive Insulin Therapy
GCSE	General Certificate of Secondary Education
GLM	Generalised Linear Model
GP	General Practitioner
GRAMMS	Good Reporting of A Mixed Methods Study
GSTT	Guy's and St Thomas' Hospital NHS Trust
HbA1c	Glycated Haemoglobin
HCP	Healthcare Profession
HIN	Health Innovation Network
IHA	Impaired Hypoglycaemic Awareness
IMD	Index of Multiple Deprivation
KCH	King's College Hospital NHS Trust
KHP	King's Health Partners
LTC	Long-term Condition
MDI	Multiple Daily Injections

MMR	Mixed Methods Research
NDA	National Diabetes Audit
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
P1	Phase 1
P2	Phase 2
P3	Phase 3
PAID	Problem Area in Diabetes
PCRN	Primary Care Research Network
PHQ	Patient Health Questionnaire
PWD	Person/People with Diabetes
QISMET	Quality Institute for Self-Management and Education Training
QOF	Quality and Outcomes Framework
QUAL	Qualitative method
QUAN	Quantitative method
RCT	Randomised Controlled Trial
REALM	Rapid Estimate of Adult Literacy in Medicine
REC	Research Ethics Committee
SE	Structured Education
SFL	Skills For Life
SH	Severe Hypoglycaemia
SIGN	Scottish Intercollegiate Guideline Network
SMBG	Self-Monitoring of Blood Glucose
SNS	Subjective Numeracy Score
SSRAL	Stanford Social Role and Activity Limitation score
STEMI	ST-Elevation Myocardial Infarction
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
TOFHLA	Test of Functional Health Literacy in Adults
UK	United Kingdom
USA	United States of America
WRAT	Wide Range Achievement Test

5 Abstract

Structured education in flexible intensive insulin therapy not only transfers skills from healthcare professional to person with type 1 diabetes to provide skills in dose adjustment, but has psychological benefit likely due to the peer support element. National and local uptake of structured education is poor. This mixed methods study used three phases to examine reasons for low uptake in two south London boroughs.

The first phase was quantitative. It used an existing local diabetes database to identify demographics and service-use differences between two groups (attenders and non-attenders) from 2006 – 2012. It illustrated demographics associated with social determinants of health, such as gender and social deprivation, influence attendance.

Phase two used both qualitative and quantitative methods; survey and interviews. A cross-sectional survey of both people with type 1 diabetes and their healthcare professionals further explored demographic and service-use differences as well as reasons for non-attendance. Semi-structured interviews with non-attenders used thematic analysis to identify four typologies; 'go-getters', 'not-yetters', 'trodden downers' and 'diabetes downers'. These were based on influential characteristics such as numerical and psychological capability and internal or external locus of control.

Phase three used focus groups with a representative sample of healthcare professionals that input into the entire diabetes care pathway, from commissioner through to person with diabetes, to discuss findings from earlier phases and reach solutions or recommendations for future interventions; such as healthcare professional training in motivational interviewing, psychological support, improved marketing and additional support for individuals with low numeracy.

The BUDiE study identified differences in demographic variables between attenders and non-attenders at structured education, the most influential being educational attainment. Four types of non-attenders were identified; go-getters, not yetters, trodden downers and diabetes downers. Integration of all three phases of the study allowed quantification of each of these types, with recommendations to improve uptake for each.

6 Introduction

6.1 What is diabetes?

Diabetes mellitus (DM) describes a group of long-term conditions (LTCs) characterised by elevated plasma glucose (hyperglycaemia) and glycosuria. DM is classified according to its pathophysiology. Type 1 diabetes mellitus (T1DM) accounts for 5-10% of all cases, affecting around 250,000 people in the United Kingdom (UK) (Health and Social Care Information Centre, 2014, National Institute for Health and Care Excellence, 2015). The incidence is 22.4 per 100,000 people in the United Kingdom but prevalence has been increasing over the past few decades (Patterson et al., 2009). It can be diagnosed at any age however the peak age of onset is 10-14 years old, meaning the majority of people have many years of exposure to this long-term condition and its potential complications. There are global differences in incidence, with variation across Europe alone from 52.6 to 11.1 per 100,000 (Finland & Slovenia) (Patterson et al., 2009).

T1DM is an autoimmune disease and is associated with human leucocyte antigen specifically the DR-DQ haplotypes (Erlich, 1991). To date there is little evidence as to what triggers T1DM and there is no current cure. There are various theories: viral attack challenging the immune system and prompting disease onset being the most mooted (Filippi and von Herrath, 2008). Auto-antibodies targeting components of pancreatic beta-cells bring about cell-mediated destruction of these insulin-producing cells. 85-90% of people with T1DM are auto-antibody positive near the time of diagnosis (American Diabetes Association, 2004). The rate of pancreatic beta-cell destruction varies, eventually resulting in complete insulin deficiency. The short-term consequences of insulin deficiency include hyperglycaemia with dehydration and the production of ketone bodies associated with acidosis (ketoacidosis). The long-term consequences, due to microvascular and macrovascular effects include: diabetic retinopathy, neuropathy and nephropathy as well as premature cardiovascular disease. To treat the insulin deficiency, people with T1DM require treatment with exogenous insulin, delivered by subcutaneous injection. The effectiveness of treatment to control plasma glucose can be monitored via measurement of glycated haemoglobin (HbA1c), which reflects average glucose concentrations over two to three months.

The landmark Diabetes Control and Complications Trial (DCCT) of the 1980s showed that intensive insulin therapy (IIT) for T1DM achieved an HbA1c almost 2% lower than routine care (9.1% v 7.3%)

(DCCT study group, 1993). This improvement in glycaemic control produced a reduction in both microvascular and macrovascular complications; 76% reduced risk of retinopathy, 60% reduced risk of neuropathy, 50% reduced risk of nephropathy, as well as 42% risk reduction in cardiovascular disease (DCCT study group, 1993, The DCCT & EDIC Study Research group, 2005, Nathan, 2014). This risk reduction came at a cost of three times more severe hypoglycaemic (SH) events (low blood glucose requiring assistance to treat) than in the control group (DCCT study group, 1993).

Those enrolled in DCCT intensive arm were supported with weekly input from a team of diabetes experts. The DCCT team felt this strategy required excessive effort and was too costly to be feasible in routine care and suggested that an alternative strategy was required to allow patients to manage IIT within the general community (DCCT study group, 1993).

6.2 How can we achieve intensive insulin therapy within routine care?

Structured education (SE) provides a potential strategy to deliver the outcomes of the intensive arm of DCCT at scale. SE empowers people to manage their health condition on a daily basis and is used in many long-term conditions, such as asthma, arthritis and heart failure (Warsi et al., 2004, The British Association for Cardiovascular Prevention and Rehabilitation, 2012, Suaya et al., 2007, Muntner et al., 2001, Dunlay et al., 2009, Anderson et al., 2016). Most SE programmes see the patient as the expert in their condition and the role of the healthcare professional (HCP) is to facilitate self-management by transfer of disease management skills. This movement away from the medical model of care is in line with the patient-centred care described by the Diabetes National Service Framework and expanded on by the Patient education working group (Department of Health, 2003, group, 2005). It gives people responsibility for their own health and encourages HCPs and patients to work in partnership to improve outcomes and quality of life.

The definition of structured patient education is fairly broad, with National Institute for Health and Care Excellence (NICE) quality appraisal 60 for diabetes defining it as *"a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual's clinical and psychological needs, and adaptable to his or her educational and cultural background*" (National Institute for Health and Care Excellence, 2003b). NICE goes on to clearly define minimum criteria for provision of structured diabetes patient education (National Institute for Health and Care Excellence, 2015). These are:

- Evidence based and suits the need of the person.

- Specific aims and learning objectives, supporting development of attitudes, beliefs, knowledge and skills to self-manage diabetes.
- Delivered by trained educators who understand educational theory.
- Quality assured and reviewed by trained independent assessors against defined criteria.
- Outcomes audited regularly.

The importance of these criteria is to ensure the fidelity of the programme, i.e. the programme is taught using the same methods and the same curriculum wherever it is delivered/implemented. They allow the transfer of knowledge from HCP to patient in a systematic way. For people with T1DM, SE can provide the skills required to self-manage flexible intensive insulin therapy (FIIT) regimens along with psychological benefit associated with sharing experiences with peers.

Systematic review of the effect of FIIT with multiple daily injections (MDI) of insulin finds reduction in HbA1c from 0.4 - 1.1% (4 to 12 mmol/mol) (Schmidt et al., 2014). Psychosocial outcomes were measured using many of the multiple validated scores available, making comparison between programmes difficult. However, the majority found statistically significant improvement, although this was not always felt to be of clinical relevance. Some HCPs worry that the increased flexibility with food choices afforded by FIIT may increase weight within T1DM populations. There is little evidence to support this, with audit data from one UK programme (Dose Adjustment For Normal Eating (DAFNE)) showing sustained improvement in glycaemic control with no excess weight gain at seven years (Gunn and Mansell, 2012). Overall FIIT programmes reduced rate of severe hypoglycaemia. The authors note that there was much variation in factors influencing outcome, for example length and delivery of course, patient factors such as numeracy and HCP factors such as enthusiasm and communication skill (Schmidt et al., 2014).

FIIT requires active patient participation, including self-monitoring of blood glucose (SMBG) at least four times per day, injecting insulin five times per day, matching insulin dose to carbohydrate intake adjusted for ambient glucose reading, as well as reflecting on recent past experience. Matching insulin dose to carbohydrate intake is a complex multi-factorial computation, requiring awareness of the pathophysiology of diabetes, nutritional knowledge, numerical skills and motivation (Kerr, 2010). Outside SE, people with diabetes spend less than two hours per year with their HCP but 352 hours per year on self-care activities (Safford et al., 2005). SE gives the patient greater autonomy and personal

responsibility for their health, whilst freeing their HCP to meet the needs of the ever-expanding diabetic population (Loveman et al., 2003).

6.3 What is the evidence for Structured Education?

The Health belief model recognises self-efficacy as an important construct mediating behaviour change (Rosenstock, 1974). Self-efficacy is the confidence someone has that they are able to carry out the task required (Bandura. A, 1977). Knowledge can increase self-efficacy in many long-term conditions (LTCs). Therefore, by providing education to increase disease-specific knowledge, HCPs are able to increase self-efficacy and thus bring about behaviour change in people with LTCs. For this reason, education is seen as playing an important role in improving health outcomes for people with LTCs as they become empowered to make daily decisions about their disease. SE, particularly when delivered in a group, or in non-clinical setting (e.g. via multimedia), is likely a more cost-effective way of increasing knowledge amongst the vast population with LTCs. Worldwide, national bodies recognise the importance of SE, recommending it for all with LTCs, as a component of quality care (National Institute for Health and Care Excellence, March 2011, Committee on quality of health care in America, 2001, Warsi et al., 2004). Despite this, SE is rarely delivered within routine clinical care but is often delivered by/in collaboration with HCPs as an additional service.

The broad definition of SE enables it to be delivered in many ways. Assessing the methodology used can be difficult, making it hard to compare the success of different programmes or their components (Warsi et al., 2004). LTCs where patients can be taught the goals of therapy, make adjustments and measure outcomes objectively, as with diabetes and hypertension, appear to respond better to SE programmes. It is difficult to recognise which components work well and which require adjustment to better suit the LTC and the audience. Warsi et al. noted this heterogeneity and recommended that SE trials should be reported using a standardised statement based on the CONSORT (Consolidated Standards Of Reporting Trials) as well as establishing a clearing house for SE trials, so that SE interventions can be investigated by someone other than the developer who has a vested interest in its success (Warsi et al., 2004, Begg et al., 1996). The hope is that these protocols will improve the standard of programmes, facilitate implementation with improved fidelity across sites and provide increased transparency (Department of Health et al., 2006).

6.3.1 Examples of Structured Education for Long-term Conditions:

6.3.1.1 Cardiac Rehabilitation:

Over the past 20 years' cardiac rehabilitation has evolved to include comprehensive secondary prevention programmes, reducing total mortality by 13 - 26% (Anderson et al., 2016, Dunlay et al., 2009, Beswick et al., 2004). The American Heart Association (AHA) and the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) therefore recommend these and have produced national quality standards. The AHA define cardiac rehabilitation as *"coordinated, multifaceted interventions designed to optimize a cardiac patient's physical, psychological and social functioning, in addition to stabilizing, slowing or even reversing the progression of underlying atherosclerotic processes*" (Leon et al., 2005). The intervention usually involves exercise training and weight management. British counterparts recognise the importance of cardiac rehabilitation in a multitude of cardiac diseases and denote it as a national priority, to be embedded into cardiology services (The British Association for Cardiovascular Prevention and Rehabilitation, 2012). They define seven key standards to ensure this happens, including identification and referral of appropriate patients, collection of audit data and the need for a defined pathway of care. The national standard delineates the core components of the education programme in detail, for example assessing drug adherence and current smoking status, whilst supporting smoking cessation (The British Association for Cardiovascular Prevention and Rehabilitation, 2012).

6.3.1.2 Asthma:

The British Thoracic Society (BTS), the Scottish Intercollegiate Guideline Network (SIGN) and NICE recommend that people with asthma are offered a self-management education course (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2014). Such programmes have been shown to reduce hospital admissions, improve symptoms and thus quality of life (Gibson et al., 2002). Current programmes are of varying duration and format, but those featuring written action plans and regular review appear to be more effective (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2014). Most programmes are still novel and undergoing evaluation, with no concrete standards yet (Muntner et al., 2001). One example is run in 75 minute sessions once per week for three weeks in a hospital setting, delivered by two physicians and a physiotherapist. At discharge from hospital patients are invited to attend the course, whose objectives are to increase confidence in asthma self-management, via integrating attitudes, knowledge and practical skills into appropriate behaviours. It

is an interactive group education programme with problem solving and limited didactic teaching. A written self-management action plan is produced at course completion(Muntner et al., 2001).

6.3.1.3 Type 2 DM: Diabetes Education and Self-Management for On-going and Newly Diagnosed (DESMOND)

This group education programme was designed in the UK for people with type 2 diabetes (T2DM) based on a philosophy of patient empowerment. It uses psychological theories of learning: Leventhal's common sense theory, the dual process theory, and the social learning theory (Skinner et al., 2006). The original curriculum was specifically designed to meet the needs of people within 12 weeks of diagnosis, and facilitates learning across capabilities. It is provided in an outpatient setting, from General practitioner (GP) practices to local supermarkets. It is delivered over six hours by two HCPs, usually a diabetes specialist nurse (DSN) and diabetes-specialist dietitian, to groups of up to 10 people with T2DM (Davies et al., 2008). Newer modes of delivery utilise peer/lay educators to facilitate the course either in English or in their mother tongue, particularly aimed at the South Asian communities. This modified version (DESMOND BME) uses culturally sensitive materials including food/meal models (Stone et al., 2008). DESMOND is widely available across UK and other countries. It is recognised by Quality Institute for Self-Management and Education Training (QISMET) (Quality Institute for Self Management Education and Training).

6.3.1.4 Type 1 DM: Dose Adjustment For Normal Eating (DAFNE)

The burden of T1DM self-management when compared with other LTCs is huge, predominantly because complete insulin deficiency means that acute complications can occur rapidly unless insulin is replaced immediately. This insulin replacement needs to be done daily without fail, and can lead to psychological 'burn out' due to the amount of additional work required (Polonsky, 1999). Particularly as longer-term complication avoidance requires precision of insulin replacement in order to achieve tight glycaemic control (The DCCT & EDIC Study Research group, 2005, DCCT study group, 1993). FIIT delivers tight glycaemic control by replicating pancreatic function as closely as possible. It requires bolus (meal-time) insulin on top of basal insulin, replacing the normal constant trickle produced by functioning beta-cells. A normal functioning pancreas also produces proportionate peaks of insulin in response to oral glucose loads. Therefore, a person with T1DM needs to understand the physiology of a normally functioning pancreas, as well as the nutritional value of the food that they are eating, in order to take on the role of their non-functioning pancreas. There are additional factors that someone without a fully functioning

endocrine system needs to consider to best manage their diabetes, such as the effect of stress and exercise and their resultant hormonal responses.

SE for FIIT therefore needs to provide a background understanding of the physiology, as well as the numerical skill and incorporate behavioural changes required. DAFNE provides this education over a five-day period by using skills based learning and other principles of adult learning to build confidence and independence in insulin dose adjustment. It is facilitated by HCPs; a dietitian and DSN, who deliver it to groups of 5-8 adults with T1DM. The course is taught in 144 locations across the United Kingdom, as well as internationally, from Ireland to Australia. It follows a standardised written curriculum. HCPs wishing to teach the course undergo rigorous training with annual peer review to maintain their certificate as DAFNE educators. People graduating from the course enter a national database, for both audit and research purposes. There are currently 35,000 DAFNE graduates in the UK (DAFNE).

DAFNE originates from the programme developed by Michael Berger and Jean-Philip Assal in Dusseldorf, Germany in the 1980s (Muhlhauser et al., 1983, Muhlhauser et al., 1987, Assal et al., 1985). The Dusseldorf programme was a collaboration between physiologist physicians (Berger and colleagues) and educationist-physicians (Assal). It was originally an in-patient programme that provided skills to manage FIIT by using a systematic approach but has since been adopted across northern Europe as both an in-patient and out-patient diabetes education course (Pieber et al., 1995).

In 1998 the Dusseldorf programme was translated to English, and DAFNE was created. British HCPs were trained by the German physiologists and educationists from the Dusseldorf programme, with the help of the education department of the University of Durham. The UK programme underwent a multi-centre randomised-control trial (RCT). The trial found a 1% (11 mmol/mol) reduction in HbA1c at 6 months after DAFNE, with improvement in psychological markers, such as quality of life and treatment satisfaction scores (DAFNE Study Group, 2002). In contrast to DCCT, there was no significant change in SH rate. A couple of years after the original RCT was published, an incremental cost-effectiveness model was produced. This used data from the RCT and DCCT to predict consequences of improved glycaemic control on healthcare costs such as diabetes complications, scheduled service use and insulin prescriptions (Shearer et al., 2004). A recently updated model based on follow-up data from the original RCT cohort concludes that at a cost of £426 per patient, DAFNE has a mean incremental cost-effectiveness ratio of £14,475 per quality adjusted life year (QALY) (Kruger et al., 2013, Speight et al., 2010). This falls well below the £20,000 threshold for NICE recommendation (Kruger et al., 2013).

Despite subsequent expansion of the programme, recommendation by NICE, and evidence for improved outcomes when integrated into routine care, the uptake of SE for adults with T1DM remains poor (discussed below in section 6.4) (Cooke et al., 2013, Gunn and Mansell, 2012).

6.4 Why is uptake to SE poor?

Measurement of data, such as key performance indicators, help drive change in standards of care by highlighting areas for improvement. The National Diabetes Audit (NDA) collects data to benchmark performance in key care processes and highlights national variation, with the hope of raising standards. The NDA is collected on an annual basis, at a set date each year. Individual primary care practices opt into reporting their practice level data. The data is based on individual NHS numbers and read codes entered at a practice level. Discrepancies may occur in the data if the wrong read code is entered, or not entered at all. This data is then analysed centrally and reports made available about 12 months later.

NDA reports national variation in referral and attendance rates at diabetes education courses. This variation is mirrored in other LTCs where rates of attendance vary from 20-50%; with 30% of people having never heard of SE for T2DM (Anderson et al., 2016, Dunlay et al., 2009, Beswick et al., 2004, Graziani et al., 1999). Variability in attendance at SE for LTCs appears to exacerbate existing health inequalities. Commonly reported barriers to attendance at SE for LTCs such as heart failure, T2DM and asthma include:

- Gender – Males are less likely to attend T2DM and asthma education, whilst females are less likely to attend cardiac rehabilitation, as they feel unsupported by their family to do so (Graziani et al., 1999, Dunlay et al., 2009, Muntner et al., 2001).
- Age – older age is associated with non-attendance at cardiac rehabilitation whilst the opposite was true in asthma (Suaya et al., 2007, Muntner et al., 2001).
- Ethnicity – People from Black and Minority Ethnic (BME) groups are less likely to attend SE. This may be associated with personal identity and lack of culturally sensitive resources (Suaya et al., 2007, Clark et al., 2012).
- Education – People with less than university level qualification were four times less likely to attend asthma education with a similar trend in cardiac rehabilitation (Dunlay et al., 2009, Muntner et al., 2001).
- Personal health – co-morbidity appears both to facilitate and prevent attendance, according to LTC. This may be associated with perceived disease severity where co-morbidities are

interdependent, for example obesity was associated with better attendance at T2DM education, but an existing diagnosis of T2DM reduced attendance at cardiac rehabilitation (Graziani et al., 1999, Dunlay et al., 2009). Perceived better pre-morbid health encouraged attendance at cardiac rehabilitation (Clark et al., 2012)

- Longer duration of disease – length of diagnosis was negatively correlated with attendance at SE for T2DM but the opposite was true for asthma (Graziani et al., 1999, Muntner et al., 2001).
- Course logistics – timing of course, accessibility of venue and distance to travel (Graziani et al., 1999, Winkley et al., 2015, Horigan et al., 2017)
- Shame and stigma associated with disease (Winkley et al., 2015, Horigan et al., 2017)

Influencing factors include:

- Perceived disease severity or insight – There is evidence that perceived severity influences attendance, with people using insulin more likely to attend T2DM SE, those with ST-elevation myocardial infarct (STEMI) or in-hospital revascularisation attended cardiac rehabilitation and those with more severe acute exacerbation of their asthma attending asthma SE (Graziani et al., 1999, Muntner et al., 2001, Dunlay et al., 2009).
- Locus of control and insight into their health – Feeling of personal health being within their control facilitated attendance at cardiac rehabilitation and people with insight into their disease or good knowledge of the educational course were more likely to attend.
- Physician or other healthcare professional recommendation (Graziani et al., 1999, Clark et al., 2012).
- Course organisation – contact with course facilitators at time of referral and telephone calls on the day prior to course start was expected to improve uptake of cardiac rehabilitation. However, completion of the course was poor, with the majority attending <5 days of the 36 days available (Dunlay et al., 2009)

6.4.1.1 Uptake of SE by adults with Type 1 DM:

The 2012-13 NDA data recorded 6,847 people as newly diagnosed with T1DM (Health and Social Care Information Centre, 2014). Of these, 260 (3.9%) were recorded as being offered and 60 (0.9%) people completed SE (Health and Social Care Information Centre, 2014). Data for those with long-standing (>12 month) T1DM shows 3.4% have been offered or attended (Health and Social Care Information Centre, 2014). The robustness of these data have been called to question, as many people with T1DM are cared

for in secondary care and referral or attendance at SE may not routinely be reported to their GP. This questionable validity is substantiated by the fact that 35,659 have completed DAFNE. This equates to over 10% of the total T1DM population and DAFNE is not the only structured education course provided for people with T1DM (DAFNE, Health and Social Care Information Centre, 2014). Since 2013 the Quality and Outcomes Framework (QOF) has included referral to SE which has resulted in improved metrics, with 32.8% of people with T1DM in England being offered SE within one year of diagnosis in 2014-15, compared to 1.6% in 2011-12 (NHS England, 2014, Health and Social Care Information Centre, 2013a, Health and Social Care Information Centre et al., 2016). However, offering a place on SE doesn't always translate to attendance.

Whichever data source is felt to be closer to the truth, attendance of around 1-20% of the population is suboptimal. Local data from Southwark, south London report less than 5% of people newly diagnosed with T1DM have attended the locally provided course (Health and Social Care Information Centre et al., 2016). Southwark and Lambeth are boroughs in south London housing two acute trusts, Guy's and St Thomas' Trust (GSTT) and King's College Hospital (KCH). Both of these trusts deliver DAFNE courses at least once per month. The combined population of the boroughs is just over 600,000, with 60% coming from BME groups. The population is young, with 42% aged 20-39 years (compared to 27% in England). The boroughs are 25 times more densely populated than the rest of England and Wales, with high turnover of residents (12% per year) (Southwark Council, May 2014). Possible explanations for low attendance rates locally include the young and culturally diverse population, with areas of high social deprivation (Hopkins. D. et al., 2013). Variation in attendance risks widening the gap in health inequalities associated with social determinants of health (Marmot, 2010).

Health literacy and numeracy have been postulated as explanations for differences in diabetes self-care between BME groups (Osborn et al., 2009). Health literacy determines how easily a person is able to find information within the healthcare system (Rothman et al., 2002, Osborn et al., 2010). Poor health literacy may lead to worse glycaemic control as a result of lack of knowledge due to inability to access and understand the literature and information offered. A recent systematic review of the effect of health literacy on diabetes was inconclusive, however it is worth noting that this was in both T1 and T2DM (Fransen et al., 2012). As described above (6.2 p3), the degree of knowledge and self-care demanded of the person with T1DM, including both the skills to compute insulin doses and the motivation to carry this out many times a day, are vast (Kerr, 2007). Technological advances bring some

assistance with this. For example, subcutaneous insulin infusion (SCII) has improved outcomes for people with diabetes (Pickup and Keen, 2002). However, the skills perceived as required to use such technology may further widen the gap between the digitally savvy and the illiterate (Buysse et al., 2013).

Despite recognition of T1DM as the exemplar LTC requiring daily self-management, and thus the absolute need for effective engagement of people with the condition in SE, there is little research into the barriers to attendance at SE. To date, the majority of work has looked at barriers to implementation of self-care processes rather than access. This work has been done in mixed (T1 & T2) or T2DM populations (Ahola and Groop, 2013, Winkley et al., 2015, Coyle et al., 2013, Graziani et al., 1999). Self-care defines a much broader group of processes that need to be carried out to care for oneself. In diabetes this includes self-monitoring of blood glucose (SMBG), healthy eating, exercise, insulin injections and daily foot checks to name but a few. SE is not itself a self-care process, but a mechanism to enhance self-care through improved disease-specific knowledge and harness the power of peer support to improve psychological wellbeing.

Work within the T1DM population has focused on young adult or paediatric populations. In this younger population multiple barriers have been identified, including socioeconomic status, family structure and on-going parental involvement. Other factors predicting self-care are personality traits, illness beliefs and mental health (Neylon et al., 2013). Mental health issues are more prevalent in people with LTCs (Ciechanowski et al., 2003). People with DM and depression have no difference in their diabetes-related knowledge, but the effects of apathy and reduced executive function may affect their ability to self-care (Egede and Ellis, 2008). Similarly to those factors outlined for other LTCs, attendance at SE is also affected by physical barriers such as transportation and work or family commitments (Winkley et al., 2015, Horigan et al., 2017).

Perceived benefit is a recurrent theme for attendance at SE in LTCs and T1DM is not excluded (Winkley et al., 2015). The Health Belief Model theorises that prior to someone adopting a health behaviour they assess the severity of their disease and its consequences, as well as barriers and benefits associated with the behaviour change (Rosenstock, 1974). Assessed severity of disease therefore influences calculation of consequential benefit from attendance at SE. This is reflected in other LTCs, with confidence in current medical management, disease knowledge, perceived benefit and pre-morbid health linked to attendance at asthma and cardiac education programmes (Muntner et al., 2001, Dunlay et al., 2009).

SE in structured FIIT provides the person with T1DM with the skills to be able to manage this, with long-term benefits to themselves and the National Healthcare Service (NHS). Little work has examined the barriers to attendance at SE for adults with T1DM and although looking at other LTCs may be of value, these populations tend to be older, often retired and may conceptualise their mortality differently, making direct translation of findings from hypertension or cardiac failure into T1DM inappropriate. The young and culturally diverse population of south London provides a perfect population to study and produce results that can be translated to other localities and LTCs

6.5 Aim of the study

This project aims to investigate the reasons for low uptake of DAFNE in adults with T1DM in south London, with a long-term objective of influencing service redesign to increase engagement with SE. My research question is: *Why is uptake of SE for adults with type 1 diabetes low amongst residents in south London?*

National and local data suggests that this problem is dual; first, only 4% of newly diagnosed adults are offered SE, indicating an issue at the level of referral, and second, only 19% of those people offered are actually attending the course, suggesting that patients have other barriers to attendance (Health and Social Care Information Centre, 2014). To investigate apparent reasons for low referral I will investigate the perceptions of the healthcare professionals looking after adults with T1DM. This will be complemented by studying adults with T1DM who have not attended DAFNE, mapping service use and baseline profiles of those people who are accessing DAFNE against those that are not, as well as investigating the reasons for non-attendance. The work will culminate in suggested changes to the current pathway/service, to enable improved uptake of this evidence-based intervention in south London (Health and Social Care Information Centre, 2013b).

6.6 Considerations for Study design

I need to consider the study design best suited to answer my research question. Methodologists advocate the importance of a well-defined question and hypothesis or purpose. The purpose of the study, either explanatory or exploratory, influence the main strategy for enquiry based on different theoretical logic (Blaikie, 2009). Inductive logic involves building theories or laws based on observations, whilst deductive logic begins with theory to produce a hypothesis which is then either proven or rejected. A combination of these produce retroductive and abductive logic (Ritchie et al., 2013). There

are two broad strategies for enquiry; qualitative or quantitative, with mixed methods providing a combination of both. The advantages and disadvantages of these are laid out below (6.6.1). My research strategy and interpretation of results will be influenced by my worldview, which needs to be acknowledged prior to commencing this study. Therefore, which research method is best used to answer my research question, given my worldview and available strategies for enquiry (Creswell and Clark, 2007)?

- My **research question** is a WHY question (why do people not attend DAFNE?)
- My **research purpose** is EXPLORATORY; suited to either quantitative or qualitative research.
- My ultimate purpose is to provide evidence to base service redesign or improvement. I therefore need to consider both the influences for this and the intended audience. Those influencing service provision decision making are unlikely to be working within the academic world, so to bring about change and have greatest impact my study needs to be easily accessible with consideration given to the translation of knowledge into evidence, that can swiftly be mobilised into practice (Greenhalgh et al., 2004).
- As a clinician, I am used to using retroductive **logic**, as I rarely have all the information needed and I make judgements according to the evidence at my disposal.
- My **worldview** is pragmatic. I believe pragmatism, as a single paradigm stance, provides a middle ground, philosophically and methodologically, although many have debated this (Tashakkori and Teddlie, 2010, Biesta, 2010). It provides a practical approach, based on actions and outcomes, suited to many research questions (Johnson and Onwuegbuzie, 2004). It supports methodological adaptability and flexibility; allowing the most appropriate method to be used to answer the research question, in response to early emerging results and external context (Patton, 2004). Research occurs within social and political contexts, which influence how findings are translated into the real world (Creswell, 2009). My findings and their translation may be effected by on-going healthcare provision, political drives toward education and financial decision making within the NHS. This is particular relevant given the introduction of Sustainability and Transformation Plans (STP). These plans are created across a large geographic footprint. Their remit is to improve quality and develop models of care, improve efficiency and improve health and wellbeing (Fund., 2017). In partnership with this is the recent increased funding from NHS England to drive improvement in four key areas in diabetes; structured education being one.

6.6.1 What methods are at my disposal?

6.6.1.1 Quantitative methods

Quantitative methods involve collecting and analysing numerical data to answer questions about how many and how much. They rely on mathematical, numerical or statistical analysis to answer these questions objectively in a predominantly deductive manner.

The advantages of quantitative methods are in:

- Testing and validating already constructed theories.
- Being generalisable if carried out on a random sample of sufficient size, reflecting the source population.
- Having the potential to make predictions or model hypotheses.
- Being often relatively quick to collect and analyse data.
- Generating results that are independent of the researcher and demonstrably statistically valid, reducing risk of bias.

The disadvantages of quantitative methods are in:

- Their need for sufficiently large samples to produce significant findings.
- Confirmation bias – the potential to miss phenomena by being hypothesis testing rather than generating.
- The potential for theories not being aligned to context e.g. local policy.
- Producing abstract knowledge, far removed from direct application (Palys and Atchinson, 2007, Teddlie and Tashakkori, 2009, Johnson and Onwuegbuzie, 2004).

6.6.1.2 Qualitative methods

Qualitative research is more difficult to define as it has no specific theory or distinct methods that are not found within other research disciplines (Ritchie et al., 2013). It is often described as naturalistic and interpretative, exploring phenomena from within (Ritchie et al., 2013). It is however well suited to answer what, how and why questions.

The advantages of qualitative methods are in:

- Being adaptable in real time, and so capable of considering the social context and allowing exploration of emergent issues.
- Providing detailed, rich and complex data.
- The reliance of their interpretation on the researcher's prior knowledge and experience, which is seen as advantageous if coupled with reflection upon this influence (Maxwell, 2008, Palys and Atchinson, 2007).
- Need for small sample sizes.

The disadvantages of qualitative methods are:

- The lack of standardisation.
- Analysis and interpretation are subject to the individual researcher's paradigm.
- Potential conflicts between the researcher and their findings, which may bias their interpretation.
- Data analysis is often time consuming.
- Results are limited in time and space, making generalisations beyond a particular time and place a matter of judgement (Blaikie, 2009).
- Researchers may be influenced by external context such as building relationships with the participants, or researching within their place of work.

6.6.1.3 Mixed Methods Research (MMR)

Mixed methods research (MMR) is emerging as a discipline. It combines qualitative and quantitative methods and is discussed further below.

The advantages of MMR methods are that they (Johnson and Onwuegbuzie, 2004):

- Integrate qualitative and quantitative methods, enabling results that go deeper and broader than either alone.
- Harness strengths and counterbalance weaknesses of qualitative and quantitative methods, by combining them (Tariq and Woodman, 2013).
- Allow broader understanding of quantitative data, by asking questions that cannot be answered numerically.

- Allow confirmation of theories arising from qualitative work.
- Are multi-faceted and well suited to answer complex questions, particularly in health (Tariq and Woodman, 2013).

The disadvantages of MMR methods are:

- As an emergent field currently establishing best-practice methodology.
- The transparency of reporting due to lack of standardisation.
- That reporting requires levels of detail not readily accommodated in the word counts accepted in high impact publications.
- That resource can be difficult to manage as experience is required in both qualitative and quantitative methodology.
- That integrating methods appropriately to get the best out of both can be challenging.
- Others believe that it is not possible to combine methods that require disparate paradigms.

My research question can be broken into smaller, more specific questions. Some are best suited to qualitative methods:

1. How do numeracy and literacy, particularly in relation to health literacy, affect attendance at SE?
2. What are the barriers to attendance at SE?
3. How could these barriers be overcome?
4. What are the enablers or motivators for those that have attended SE?

Whilst others are better suited to quantitative methods:

1. What is the current rate of attendance locally?
2. Are particular groups less likely to attend SE than others?

While some of these questions could be addressed using either quantitative or qualitative methods alone, I concluded that my objective is best met by using a combination via MMR. This will allow the integration of data from both methods to provide a better insight than simply using one. MMR provides answers to a complex question by providing both a broad and deep understanding of the problem. MMR also allows consideration of the contextual issues producing a robust evidence base from which to adopt change. This is particularly relevant given that recent interest in SE has produced little change in uptake,

likely due to strategies being based on audit data and anecdotal evidence rather than robust research (Health and Social Care Information Centre et al., 2016). Used well, MMR will allow me to harness the strengths of each methodology to produce a truthful illustration of the diabetes SE landscape which will be applicable across south London to inform decision makers wishing to increase attendance. I believe that a robust recruitment strategy will ensure my findings are generalisable to other populations.

6.7 Mixed Methods Research (MMR)

6.7.1 Background

MMR has been practiced since 1959 making it a relatively new method, which is still evolving. Creswell and Plano Clark describe it as a methodology that '*focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or a series of studies'* (Plano Clark and Creswell, 2008) However this definition is not shared by all. When Johnson et al. polled twenty-one academics to define MMR they received nineteen different answers (Johnson et al., 2007). However defined, MMR clearly involves the use and integration of both qualitative and quantitative methods to answer one research question. The National Institute of Health has set out best practice guidance for the use of MMR, defining five key components (Creswell et al., 2011):

- Focusing on research questions that call for real-life contextual understandings, multi-level perspectives and cultural influences
- Employing rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs;
- Utilising multiple methods (e.g. intervention trials and in-depth interviews)
- Intentionally integrating or combining these methods to draw on the strengths of each; and
- Framing the investigation within philosophical and theoretical positions.

6.7.2 Rewards and Challenges of using MMR

MMR addresses research questions that call for real-life contextual understanding by providing multiple perspectives on different levels, from the macro picture of the population and service provision to individual stories describing hard-to-measure phenomena (National Institute of Health; Office of Behaviour and Social Science Research). The use of MMR in my study will allow robust qualitative data to broaden our understanding of a complex phenomenon not yet investigated (Johnson and Onwuegbuzie, 2004). The qualitative component draws on real-life experiences and participant voices,

looking at emergence of processes over time to produce inductive theory-driven research, whilst the quantitative component examines the magnitude of the problem through frequencies, numerical data and outcomes that can be analysed statistically to provide deductive research that has measurable evidence (National Institute of Health; Office of Behaviour and Social Science Research). Often qualitative material found in surveys taps the consciously available cognitions i.e. reason-based explanations, attitudes and beliefs, but misses the symbolic, experiential and emotional material that drive cognitions and behaviours (Joffe, 2011). On the other hand, qualitative or anecdotal evidence may have little ability to drive service changes on their own, as they are not grounded in quantitative data which is generalisable and meets the needs of the wider community. The combination of the two disciplines, via MMR, will produce well-founded and defensible findings, supporting wide inference and future implementation, speaking directly to those involved in financial decision making within the NHS, where resources are scare and the needs of the masses must be met over and above the niche.

There are challenges in combining research paradigms. Although one of the attributes of mixing methods is the opportunity to produce an outcome that is more than the sum of the inputs, this is also a potential downfall as it risks producing conflicting results from each method. I need therefore to consider this possibility and how to deal with it, particularly if I generate results that are contradictory. This is discussed further below (7.2.3).

A second challenge is the skill set required to practice MMR. To properly understand the methods, sufficient time and resource is required. This puts pressure on resources associated with gathering and analysing different sorts of data during the multiple steps involved, as well as learning the different skills employed for each method and analysis (Creswell, 2009). This study constitutes a doctorate project and therefore I have the luxury of devoting three years to learn the skills required (Appendix A).

An additional challenge for MMR is the effect of the research on the study population (Creswell and Clark, 2007). My population may be altered because of the sequential study design. A participant may complete the questionnaire enquiring into certain aspects of healthcare, be prompted to find out more information and may then attend a focus group with a different views or beliefs than at the start of the study.

6.7.3 MMR methodology

Describing an emergent field, the MMR nomenclature can be confusing and often overlapping, with different ways to describe the same or similar study designs. To improve the transparency of study reporting various frameworks and guidelines have been produced. In 1989 Green et al. laid out one of the first conceptual frameworks for MMR (Greene et al., 1989). They identified five different study purposes and described the varying methods, paradigms, method dominance and implementation that best suits each. 20 years later the discipline remained confused. O'Cathian and colleagues reviewed 75 MMR studies and described inadequate reporting of the justification for study design, little report on the qualitative methods and a lack of method integration (O'Cathain et al., 2008b). This review led to production of the Good Reporting of A Mixed Method Study (GRAMMS) tool which I will use to describe my study in the following chapter (O'Cathain et al., 2008b).

7 Methodology

7.1 The Barriers to Uptake of Diabetes Education (BUD1E) Study

Investigation into the Barriers to Uptake of Diabetes Education (BUDiE) in adults with T1DM in Southwark and Lambeth, London.

7.1.1 Regulatory Approvals and Study Registration:

The research protocol is approved by National Research Ethics Service Committee (REC) London – Dulwich (14/LO/1751)

The study is UK Clinical Research Network (CRN) portfolio registered – 17842

The study is funded by a grant from the South London Collaboration for Leadership in Applied Health Research and Care (CLAHRC) and fellow stipend paid by Health Innovation Network, (Academic Health Science Network (AHSN)) South London.

Additional funding received from CRN for help with recruitment.

7.1.2 Steering and Advisory groups

Service users have been involved in my study from the start. The initial involvement was ad hoc, asking people in local diabetes clinics for their thoughts on information leaflets. Within a few months of beginning recruitment to BUDiE Study I set up an advisory group. This group consisted of seven people who had already participated in the study. We met every four to six months over the study period to discuss iterative changes to recruitment and study design, topic guides for interview and sense check findings. One person from the advisory group (AM) joined the research group to help with analysing the data. He was involved in qualitative analysis, described below (7.5.2) particularly coding and producing themes, providing a different perspective.

Additionally, a steering group was set up from the outset of the study. This consisted of my PhD supervisors and other experts in diabetes education and/or research. This group met quarterly. I also had input from specialists in the field of both MMR and qualitative research, with training needs met via King's College London (KCL) or external courses.

7.2 Mixed Methods Research

Below, I will use the GRAMMS tool (discussed in 6.7.3) to describe my project; laying out different strategies available, choices made and why.

7.2.1 Justify the use of a mixed methods approach to answer the question.

This study has an exploratory purpose; wishing to understand a complex issue - reasons for non-attendance at SE. SE is provided free at the point of delivery within the framework of the NHS to people with T1DM however attendance is unlikely to be dependent solely on one individual's decision. There are likely to be multiple factors influencing attendance, including how it is provided and financed locally. My study examines each stage of the SE pathway (Figure 7-1) from commissioning the service, through to attending a course, to identify influential contextual factors at each stage.

Figure 7-1: A simplified view of the SE pathway from commissioner to person with T1DM

I could use quantitative research methods to describe the number of people not attending SE. This approach would produce theoretical barriers based on quantitative findings, and further confirmatory studies would then be required. Alternatively, qualitative research would produce reasons for non-attendance within a small group of study participants. This would not quantify the size of the problem, thus be of little value to professionals involved in service re-design, who need to prioritise according to population cost-benefits. MMR allows both a broad and deep understanding of the problem; defining both the reasons for non-attendance, and measuring the proportionate size of each barrier. MMR will deliver results which are grounded in opinion but transformed into numerical data; talking more directly to those involved in healthcare decision making to greater impact services.

7.2.1.1 Describe the design in terms of the purpose, priority and sequence of methods

7.2.1.2 Purpose

The purpose of this study is to explore reasons for low attendance at SE for adults with T1DM. Having chosen to use MMR, it is important to understand the purpose of mixing methods, and what will be

gained or lost by doing so. Newman et al. describe six types of research purposes (Tashakkori and Teddlie, 2003):

- Predict
- Add to knowledge base
- Have a personal, social, institutional and/or organisational impact
- Understand complex phenomena
- Test new ideas
- Inform constituencies
- Examine the past

I can identify my study purpose in:

1. **Adding to the knowledge base** by being an academic (PhD) project, collecting new data and analysing it within an academic environment.
2. **Understanding complex phenomena** ranging from behavioural choices in LTCs to system thinking in terms of commissioning and providing SE.
3. **Having a personal, social, institutional and/or organisational impact** due to being conducted by a developing researcher and clinician, where there will be personal development associated with learning new methods and the opportunity to further understand decision making associated with LTCs. Additionally, I hope to have organisational impact as findings reach the wider community, influencing redesign choices. To achieve this, my study needs to be comprehensible to the non-academic world. Occasionally, this dual purpose may be counterintuitive, however I will produce an academically robust piece of work that translates into a meaningful report for use within the NHS.

7.2.1.3 Priority or Dominance

MMR reporting standard uses capitalisation to delineate the dominant methodology, using QUAL and QUAN as shorthand for qualitative and quantitative. Whilst GRAMMS talks of the need to describe the priority given to individual methods, other methodologists use the word dominance or weight (Greene et al., 1989). In this thesis, I use 'dominance'. This describes the dominance given to either qualitative or quantitative methods or the complete equality of them. It is unhelpful to consider quantitative and qualitative research in terms of the methods used. It is the data collected, the quantities (expressed as

numbers) and qualities (usually expressed as text, but can be numbers) that defines the term, rather than the method used to collect the data (Biesta, 2010). Therefore, the dominance reflects the data output rather than the method used.

Contextual factors, such as my intended audience, have affected my decision regarding methodological dominance (Creswell and Clark, 2007). I intend my study to influence the academic world as well as decision-makers, particularly commissioners, considering their annual spend on healthcare and provision of SE programmes. With this dual purpose in mind, I believe my study requires quantitative dominance to achieve greatest impact within its intended audiences. Quantitative research has traditionally been the dominant method in healthcare settings, producing a workforce comfortable with interpreting quantitative findings. Research in other LTCs has identified barriers to attendance at SE, leading to innovative ways to engage those not attending, however attendance rates still remain low (Winkley et al., 2015, Diabetes UK, 2016). Quantitative dominance in my study will allow quantification of the non-attending population to different barriers, enabling those involved in service redesign to make decisions based on meeting the needs of the larger groups and have greatest effect.

An alternative way to increase impact is via dissemination in academic journals. MMR traditionally has difficulty publishing findings in high-impact journals, often due to restrictive word counts (Creswell et al., 2011). Quantitative results are more likely to be published in high-impact journals, further increasing influence (Creswell and Clark, 2007). Other contextual factors influence dominance decision making, including the research team and its skill set, particularly when researchers have prior experience in one methodology (Fetters et al., 2013). As a clinician, I have greater experience of quantitative methods and although my learned communication skills are of value for interview/focus group work, I had not been formally taught qualitative research prior to commencing my PhD. To build confidence and competence in qualitative skills I have accessed specific training courses within the post-graduate school (Appendix A) and sought support from senior academics.

7.2.1.4 Sequence

Timing or sequence refers to the temporal relationship between the two different elements within a study (Creswell and Clark, 2007). The most important factors are the timing of the analysis and interpretation of the data, rather than the collection. Good MMR reporting discloses when and in what order the separate methods were utilised. This is interlinked with describing the integration of the

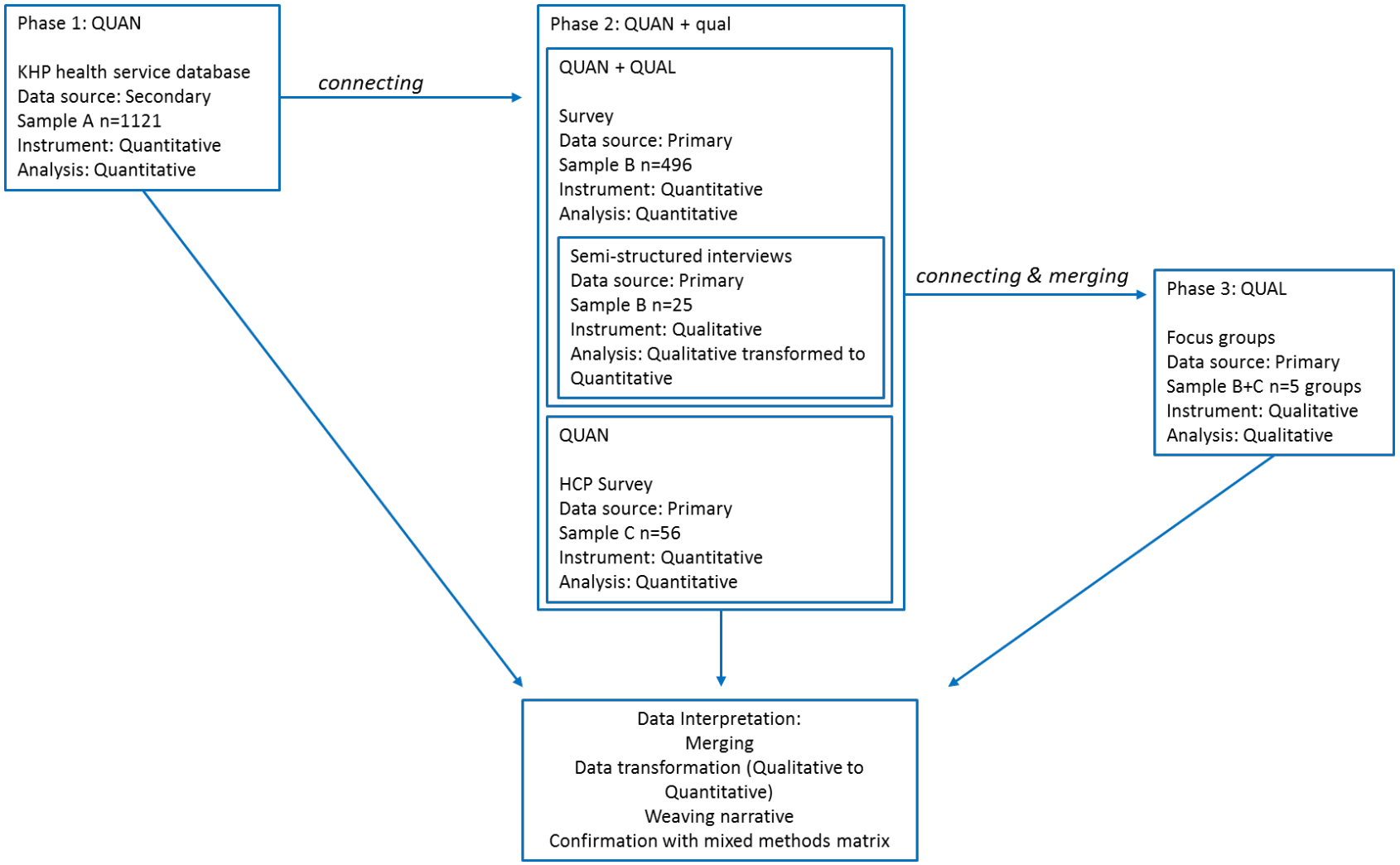
methods, and reliance of each method upon the other. I have used the recognised MMR study design illustration standards to demonstrate methodological dominance (capitalisation indicates dominance) as well as the sequence of events (+ or -> indicate concurrent or sequential) below in Figure 7-2 (Creswell and Clark, 2007).

Broadly there are four different types of mixed methods study (Creswell and Clark, 2007, Fetters et al., 2013):

- Triangulation design collects data separately and converges the results together at a time point. O'Cathain et al. describe triangulation as occurring only at the interpretation phase, when comparison of convergence and discrepancy between the two methods raises areas for discussion or further investigation (O'Cathain et al., 2010). The premise of triangulation is that each method brings its own biases; and that simultaneously using two different methods to examine the same thing, adds weight to each other's findings (Greene et al., 1989).
- Embedded design mixes data at the design stage. This is needed when one data set is insufficient to answer the question. Usually one method is dominant, the other playing a supporting role.
- Explanatory sequential design uses two data sets with the first (usually quantitative) feeding into selection or design for the second stage (usually qualitative), e.g. database analysis indicating specific outliers or population for interview sampling.
- Exploratory sequential design uses two data sets with the first (usually qualitative) informing subsequent quantitative data collection e.g. focus groups identifying key themes which can then be measured in a larger group questionnaire.

My study used a predominantly explanatory sequential design with initial quantitative research results contributing to subsequent elements of the design. It used a fixed model that was broken into three phases. The sequential design allowed for elements of each phase to contribute to decisions being made in other phases. The fixed model predetermines the methods used and strand required, but connects the results to let each strand influence the other (see Figure 7-2).

Figure 7-2: The phases of the MMR study design illustrated using extended MMR notification (Cameron et al., 2013) used with addition of italicised description of integration methods.
n = number in sample, QUAL = qualitative, QUAN = quantitative (UPPER case denotes dominance), + = concurrent, -> = sequential.



The first phase used quantitative methods. The second phase had a concurrent design with data being collected at the same time, from the same sample. The final phase used qualitative methods, with the results from both phase one and two contributing to the study design. Each phase had different degrees of integration with, and contribution to, subsequent phases.

7.2.2 Describe each method in terms of sampling, data collection and analysis

The three phases involved in this study are illustrated in Figure 7-2. Because of the iterative design, additional details of the sample, collection and analysis methods are described in the chapter associated with each phase.

7.2.2.1 Phase 1 (P1)

The first phase of this study utilised quantitative research methods. I used an observational cross-sectional design. The sample was taken from a local service use database. The results from statistical analysis at the end of phase 1 (P1) influenced design of phase 2 (P2). Further integration of P1 results occurred at the end of all phases.

7.2.2.2 Phase 2 (P2)

The second phase used both qualitative and quantitative methods, with equal dominance. Further information about the qualitative and quantitative methodology is outlined below (7.4). Data was collected concurrently with P1. Two separate samples were used:

1. One sample (Sample B) was used for both qualitative and quantitative research. It consisted of people with T1DM (PWD) living in Southwark and Lambeth aged 18 years or over. This sample undertook cross-sectional survey study and semi-structured interviews.
2. The second sample (Sample C) comprised HCPs involved in providing or referring to SE courses for T1DM. This sample was taken primarily from the local NHS trusts and surrounding GP surgeries, with additional "snowball" recruitment (using clinical networks) to include south of England. Sample C completed a questionnaire

The results from the qualitative and quantitative elements of this phase were analysed separately, with some merging and connecting to influence phase 3 (P3) (7.2.3).

7.2.2.3 Phase 3 (P3)

The last phase used qualitative research methods in the form of focus groups. These focus groups were made up of PWDs, taken from Sample B and HCPs, taken from Sample C, as well as professionals involved in strategic decision making, such as commissioners and public health consultants. The early results from P2 influencing the topic guide and focus of the discussion. The results from P3 were analysed separately and interpreted in combination with earlier results, outlined below (7.2.3).

7.2.3 Describe where integration has occurred, how it has occurred and who participated in it.

One of the most important aspects of MMR is the combining, mixing, integrating or merging of methods. As previously discussed, this is done poorly across the MMR community and runs the risk of underutilising either method at a cost to both the research team and the study outcomes (O'Cathain et al., 2008b, O'Cathain et al., 2010). The emergent nature of MMR and the flexibility of integration, according to research purpose, throughout a study (both type and timing) results in novel methods and potential confusion in terminology. This may explain why there is such poor reporting of it within MMR studies (O'Cathain et al., 2008a). For example, in the early 21st century Creswell et al. described three main ways to integrate at method level – connecting (using one result to influence the next stage, data linked within a sampling frame), merging (reporting data together/transforming data) and embedding (Creswell and Clark, 2007, Creswell et al., 2011). However, by 2013 there was an additional method, building (Fetters et al., 2013). To add to the confusion embedding is often described as requiring quantitative dominance, as it is usually qualitative work embedded into a larger randomised control trial, however recent guidance fails to mention the need for dominance (Fetters et al., 2013, Creswell and Clark, 2007).

Integration can occur in many ways, and it is important to report where and how this has been done to maintain transparency and increase understanding of MMR amongst the wider academic community. The level at which integration may occur can be simplified into three key levels, with numerous associated study designs (**Error! Reference source not found.**) (Fetters et al., 2013). I have reported my study using these different levels, with discussion and examples provided below.

Level	Design	Description
Design	3 basics 4 advanced frameworks	Exploratory sequential Explanatory sequential Convergent Multi-stage Intervention Case study Participatory
Methods	4 approaches	Connecting Building Merging Embedding
Interpretation/analysis and Reporting	3 approaches	Narrative Data transformation Joint display

Figure 7-3:: Table outlining the different levels at which integration can occur within a study, with associated design and description (taken from Fetters et al)

7.2.3.1 Design level

- Utilising an exploratory sequential design ensures the data are linked between phases with early findings being utilised in consecutive phases.
  - For example, the quantitative results from P1 identified key demographic factors, instrumental in influencing attendance at SE. This dictated the variables and proportions for the interview purposive sampling.

7.2.3.2 Method level

- Connecting
  - For example, early results from the survey in P2 suggested certain barriers which were incorporated into the interview topic guide. In addition, an advisory group (7.1.2) made up of early respondents from Sample B helped design the interview and focus group topic guides, adding another level of integration.
- Merging
  - Merging of data occurred prior to P3; with results from P1 and P2 being merged to influence the P3 topic guide.

7.2.3.3 Interpretation and analysis level

- Triangulation was used across all phases of my study
  - The results from P1 and P2 were analysed separately but interpreted together, to influence the design of P3, particularly the topic guide and choice of attendees.
  - Triangulation was used to bring together the results from all phases, particularly concentrating on verifying and expanding positive findings from individual phases. Results were merged and interpreted with a focus on barriers and potential solutions. Weaving narrative 'followed a thread' of particular interest through my study, by identifying questions or components after preliminary analysis, and following these through the data (O'Cathain et al., 2010). This was of particular value when questioning potential explanations for quantitative results that were found in the qualitative work.
- Data transformation was used in P2.
  - Sample B lent itself well to 'quantisising' of qualitative data, as both quantitative and qualitative data were collected from the same sample (Tashakkori and Teddlie, 2010). After preliminary analysis, the individual cases, rather than variables or themes, were compared and contrasted (O'Cathain et al., 2010, Wendler, 2001). This second level analysis involved creation of a mixed matrix, transcribing into it, coding data, seeking commonalities, and pattern recognition. This allowed complex text to be turned into numerical data, enabling visualisation of emerging patterns that may not have been apparent if the data had been analysed separately and interpreted using other means.
  - Three different types of matrix exist: comparative, pattern and similarity. I used both comparative and pattern matrices. For example, answers to the validated scales in P2 survey were compared to my translation of similar constructs taken from the same individual's interview transcripts. This helped validate my interpretation of the interview data, enabling sense checking and providing an opportunity to highlight any bias and reflect upon it. It also allowed scrutiny of the validated scores as there can often be inconsistencies in completion of scaled scores (Green et al., 2008, Bazeley, 2010). Pattern finding was used to visualise emerging themes or typologies from the Sample B interview data. Themes emerging from the data were colour coded to enable visualisation and aid confirmation of emergent typologies.
- Open question survey responses about enablers and barriers were combined with interview data. Emergent themes from the survey responses were mapped onto the barriers and

enablers identified in the semi-structured interviews. The level of concordance between these three data sets (Sample B survey, Sample B interviews, Sample C survey) were assessed and explanations sought for discordance or new emerging themes that had not been initially apparent.

At the end of my study I considered how knowledge had been enriched by using mixed methods. If MMR had added no supplementary value then it was likely integration had not been achieved and I would need to re-examine my data (Tariq and Woodman, 2013). Creswell et al. suggest checking the fit or unity of the data by considering the extent of agreement (confirmation, expansion or discordance) (Fetters et al., 2013). Confirmation and discordance are self-explanatory, whilst expansion describes a scenario where the two data sets diverge but enlighten, expanding on the understanding of the phenomena in question.

I checked the extent of agreement across all phases, particularly focusing on barriers and enablers to SE. Discordant findings prompted me to return to the primary data to verify or expand knowledge. Additionally, discordance or expansion that had not been anticipated was reported. This transparency enables the reader to reach their own conclusions, based upon the strengths and weaknesses of each method used and the level of discordance seen. There were two areas at which discordance was anticipated to occur; the comparison of 'quantisised' interview data with validated scores from the surveys, and at the point of triangulation when results from all three phases were brought together for analysis.

7.2.4 Describe any limitations of one method associated with the presence of the other method

GRAMMS reporting expects a description of methodological limitations. This is reported in the final chapter 17).

7.2.5 Describe any insights gained from mixing or integrating methods

The description of insights gained from using MMR is reported in the final chapter (17), where I have reflected upon the advantages and disadvantages of using MMR as well as insights gained.

7.3 Recruitment methods and population

7.3.1 Recruitment considerations

My study into barriers to SE in south London needed to collect data from all involved in delivering and attending SE, from commissioner to individual with T1DM. I wanted to collect proportionate data, so concentrated recruitment efforts on those with T1DM, as they are a much larger population than service providers or commissioners.

7.3.1.1 Phase 1:

Phase 1 (P1) involved cross-sectional observational study using a pre-existing service use database. This database was a composite of three data sources:

1. Retinal screening database (diabetes eye complication screening (DECS)) which holds demographic and contact details for individuals with a diagnosis of diabetes living in Southwark and Lambeth (more detail provided below in section 7.3.1.2.1).
2. King's Health Partners (KHP) diabetes database which collects demographic and service use data for individuals using either KCH or GSTT diabetes services. This database holds data from January 2006 until present day, however for my project I analysed data from 2006 until December 2012.
3. Local DAFNE database which collects data for all individuals who have graduated (completed) DAFNE.

The combination of these three databases allowed identification of individuals with T1DM living in a defined geographical area, using the local hospital services, with or without DAFNE attendance. This generated sample A. The pre-existent nature of the database, meant that direct recruitment was not necessary, and pseudo-anonymised data was used in my project.

Sample A inclusion and exclusion criteria were:

Inclusion	Exclusion
18 years old or more	Chronic kidney disease stage 5 (due to assumed high service use)
Resident in Southwark or Lambeth boroughs of London	
Diagnosed with T1DM	
Using KHP diabetes services	

Margin of error calculations based on a sample size of 1107 and a national population of 250,000 (based on NDA data) produces a 0.42% margin of error at 0.005 significance (Health and Social Care Information Centre, 2014).

7.3.1.2 Phase 2 and 3:

Phase 2 (P2) involved a cross-sectional survey study from two separate samples (B and C), with semi-structured interviews of a proportion of survey respondents. Sample C consisted of HCPs involved in caring for adults with T1DM, and is described below in more detail (7.3.1.3).

Sample B inclusion and exclusion criteria were:

Inclusion	Exclusion
18 years old or more	Other types of diabetes
Resident in Southwark or Lambeth boroughs of London	Non-resident or asylum seeker
Self-reported T1DM	Unable to consent for themselves
Diagnosed more than 6 months prior to recruitment	

Results from P1 identified demographic characteristics associated with non-attendance at DAFNE which influenced my study design. Therefore, my study required certain groups' opinions to tailor intervention recommendations to their needs. However, traditionally harder to reach populations are less willing to engage in research, particularly the young, men, BME groups, low income and lower educational level (Sheldon et al., 2007b).

Recruitment needed to utilise strategies to target these groups. To measure the success of recruitment and gauge generalisability of the results I recruited from a pre-defined population based on geographical location. This allowed me to estimate proportions from each demographic group and ensure fair representation in the survey responses. I used an iterative recruitment method and survey design to maximise the response rates within my target population. This strategy minimised response bias and maximised participation of the seldom heard voices. Other recruitment and response barriers were considered, such as literacy levels, visual problems and language difficulties (which have been shown to be barriers to attendance at SE in T2DM) (Osborn et al., 2010).

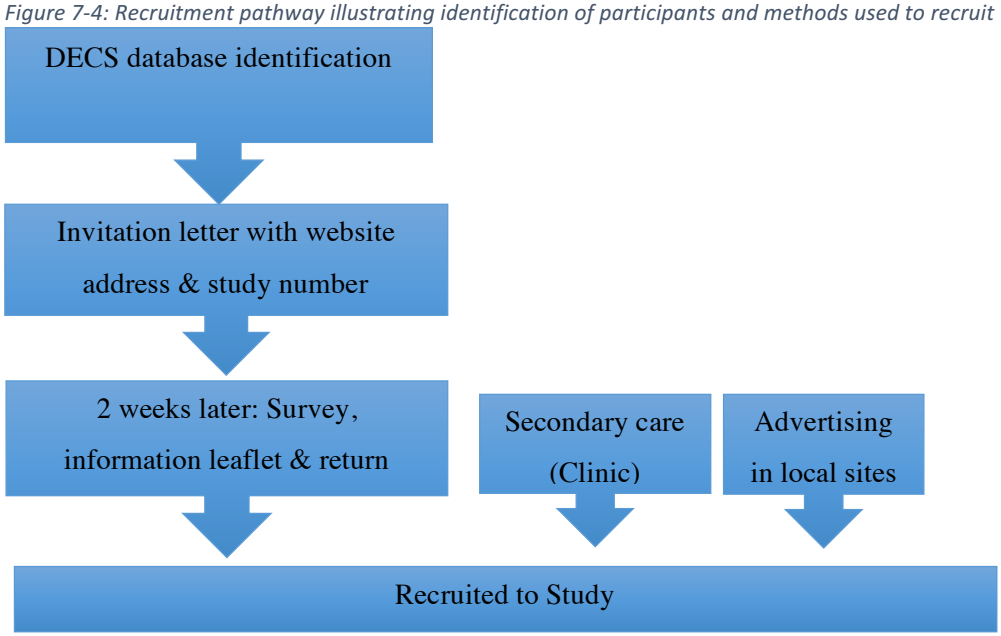
Due to the diversity of languages spoken locally the study information was not translated into multiple languages, but a footer was included on the invitation letter in the four most commonly spoken

languages (taken from local census data), inviting contact with the study team for additional information or help (Southwark Council, May 2014). Where necessary, translation was offered by professional telephone service.

A power calculation based on the number of people registered with DECS in Southwark and Lambeth with T1DM (1500 adults) suggested a sample size of 306 to achieve 95% confidence interval and a margin of error of 5% . My study success relied on gathering opinions from those who are often last to speak out or contribute to research, so I aimed for a response rate of at least 33% (500 people).

Participation was voluntary, with potential participants being made aware that their healthcare was unaffected by their choice. Completion of the survey was incentivised with a £5 gift voucher, and interviewees received £25 gift voucher. Consent was implied by completion of the survey, whilst written consent was taken for interview participants. The recruitment pathway is described and illustrated below (Figure 7-4)

Figure 7-4: Recruitment pathway illustrating identification of participants and methods used to recruit them.



7.3.1.2.1 Retinal screening database

People with diabetes of any type should receive annual screening for retinopathy to enable early detection and prevent blindness. Until recently 'people with diabetes attending retinal screening' has been included in the QOF standards, including 2013/14 (NHS England, 2014). Incentivising of referral results in DECS holding the most up-to-date and complete record of people with diabetes registered with a GP in Southwark and Lambeth, independent of where they receive their diabetes care. This live database includes people receiving treatment for eye disease within the ophthalmology service, as well as those currently undergoing screening. Data sharing regulations mean that DECS has limited information for each referred patient but collects more detailed self-reported information (including type of diabetes) at appointment visit. People who have not yet attended DECS do not have their diabetes type identified. DECS have a clearly defined, opt-out, policy on information sharing between the screening programme and NHS trusts/healthcare professionals (Appendix D).

The DECS database was used as the primary source from which to recruit to the BUDiE study. It identified eligible participants and provided their contact details. Additional opportunistic interactions with care givers were used as a secondary source, or a means to remind people of the study.

The DECS retinal screening team used its database to identify eligible participants and invite participation on behalf of the research team. They sent an invitation letter (Appendix E) outlining the

contact details) and advising that a paper questionnaire would be sent via post within 2 weeks. Two weeks later the study survey and patient information leaflet (Appendix F & G) was sent to those who had not responded. Undelivered surveys were returned to the study group via return address envelopes, to enable more accurate calculation of response rate. Those receiving the initial invitation letter who did not wish to participate could directly contact the study team or return the letter to sender. Each potential participant was assigned a unique study number, used in all communication, allowing identification of respondents by the research team and increasing confidentiality if participating in the online survey.

An initial first wave of 500 participants was invited. Early analysis of the success of recruitment informed further changes. All data was included in the final analysis.

7.3.1.2.2 Healthcare settings

Primary and secondary care professionals were made aware of the study via letter. In diabetes outpatient clinics at KCH and GSTT potential participants were provided with information about the study (Appendix F) and, where willing, given a survey to complete. Participants could complete the survey in their own time, making use of the pre-paid return envelope, or alternatively using the website address and study number to complete it online.

This strategy of recruiting directly from secondary care settings meant that some eligible participants had multiple contacts with the research team, as they received postal invitations in addition to being approached in clinic.

7.3.1.2.3 Community settings

With consent of the primary/community care team and local sites (e.g. pharmacies, shops and religious places) literature about the study was placed in prominent places. This contained website address and quick response (QR) code to enable participation in the survey at the click of a button on a smartphone. Respondents participating via this route did not have a study ID number, making them anonymous and it impossible to accurately measure response rate. They were asked to provide an email address so that a gift voucher could be given to them and in case of their Patient Health Questionnaire (PHQ)-9 raising possibility of depression (see 7.4.2.2).

Individuals willing to participate in the BUDiE study from Sample B were given the option to complete the survey and/or to participate in the semi-structured interviews or focus groups. I

providing both quantitative and qualitative data for these individuals; facilitating integration at analysis level. Purposive samples were invited to participate in the semi-structured interviews and focus groups. Only individuals who had not attended DAFNE were invited to semi-structured interview, whereas the focus groups included both attenders and non-attenders.

7.3.1.3 Study population: Sample C

Sample C inclusion criteria were:

- Healthcare professional (HCP) registered with appropriate professional body
- Currently working within Southern England, with a focus on Southwark and Lambeth boroughs, London.
- Caring for people with T1DM

HCPs were already aware of the study due to their involvement in recruitment of Sample B from their clinical settings. I also presented at GSTT and KCH diabetes clinical team meetings. Secondary and primary care clinicians were invited to participate in the survey. All members of the diabetes multidisciplinary team were included and GPs with special interest in diabetes were specifically invited. Additionally, professional networks across southern England disseminated information about the study. This later recruitment strategy made it impossible to assess response rate, but was necessary to produce generalisable findings and broaden understanding of the professional barriers to attendance; particularly as many areas of the country do not regularly offer DAFNE, if at all.

HCPs were invited to participate via email. The email contained information about the study including address for the online survey. This was followed by reminder emails. The survey was anonymous with no personal or correspondence details collected. Study numbers were assigned on receipt of a completed survey.

Focus groups included HCPs and people involved in commissioning. Participants were invited from Southwark and Lambeth, as well as neighbouring south London boroughs, to provide a broad experience base. Due to the anonymity of the survey I did not know whether these individuals had completed a survey or not.

7.4 Quantitative Methods

In this section, I will discuss design considerations as well as analysis of the data. Much of the quantitative data analysis is similar across P1 and P2, where methods differ they will be described separately.

7.4.1 Design considerations

Quantitative methods are suited to defining populations and producing widely generalisable findings. For my study, it is suited to answering questions about the number of people attending SE, defining their characteristics and looking for any statistically significant associations. P1 used a cross-sectional observational design, utilising an existing service use database. Whilst P2 used cross-sectional design using survey of two independent samples, B and C. Previous research has used pre- and post- survey design to assess the impact of DAFNE and drawn conclusions based on the demographics of those attending (Cooke et al., 2013, Gunn and Mansell, 2012). To date, nobody has carried out cross-sectional observational research to quantify characteristics of the non-attender population. Non-attendance was defined as having not completed a SE course, and therefore included a range of people; from those who had walked out halfway through a course, to those who had never heard of the course let alone been offered a referral.

A postal survey allowed me to reach a large geographically dispersed population in a short space of time. It had potential to reach those not attending secondary or primary care as well as allowing people time to respond in the comfort of their own home. An online format provided the additional benefit of being more cost-effective, as data automatically entered a spreadsheet and postal costs were avoided. In my predominantly young working population digital exclusion via online surveys was unlikely to pose a problem, however I made both paper and online versions available (Go On, 2015). For the HCP population there was an online survey only. This minimised costs, and enabled the survey link to be sent via social media and newsletters, for easy dissemination amongst networks to reach a wider audience. Although this created anonymity amongst HCP respondents it made it impossible to count the number of people invited to participate, and calculate response rate.

Thought needed to be given to the survey design, not only the content but also the aesthetic. A systematic review of postal surveys identified 75 strategies and various factors increasing response rate (Edwards et al., 2002). These included:

1. Monetary incentive where a non-linear relationship exists between financial reward and

2. The use of colour
3. Registered mail
4. Brevity, with a non-linear relationship between number of pages and response rate.
5. Personalisation of the invitation letter
6. Contact with participants before and after a survey is sent
7. Self-addressed returns envelope

I considered these and included prepaid return envelopes, use of colour and including individuals' names on invitation letters for Sample B. The survey was divided into sections to reduce the burden, with the most important questions first. Participants received the gift voucher (£5) if the first two sections were completed.

Both surveys were piloted; Sample B survey on four PWDs visiting KCH diabetes clinics who resided outside Southwark and Lambeth and Sample C survey on two HCPs working outside Lambeth and Southwark. Individuals were asked to comment on the wording of questions, the level of understanding and use of jargon, as well as burden, brevity and overall aesthetic design. Their feedback influenced final survey design, invitation letter and information leaflets.

7.4.2 Study Design

7.4.2.1 Phase 1

P1 provided an opportunity to analyse differences in demographics and service use between people who had and had not attended DAFNE from 2002 to 2012. Baseline data were used to assess influencing factors. However, consideration was needed to overcome the fact that individuals can attend DAFNE at any time-point during their diagnosis with T1DM. Additionally, DAFNE has been available since 2002, whilst the KHP service use database came into existence in 2006.

The database was anonymised; NHS numbers were replaced by randomly generated study identification numbers, dates of birth were converted to age and address details were deleted after assignment of index of multiple deprivation (IMD) scores from Office of National Statistics tables (Department for Communities and Local Government and The Rt Hon Eric Pickles, 2010). The local DAFNE database of graduates was used to divide the KHP database by attendance or not at DAFNE. For each year, from 2006 to 2012, a proportion of non-attenders were arbitrarily allocated to a year of intervention (I), using a random number generator, to create a control group. The baseline data was then collected for the attender and non-attender groups in the two years preceding (I-2).

Individuals who had attended DAFNE prior to 2008 did not have sufficient data for I-2, therefore their demographic data alone was included in analysis.

The data collected included:

- Age
- Gender
- Ethnicity
- IMD score
- Duration of diabetes
- HbA1c (taken as an average over 12 months, and consecutive readings within a 3-month period excluded from analysis)
- Diabetes specific service use (including scheduled and un-scheduled services, as defined by specific codes)
- Accident and Emergency (A&E) attendances (due to anecdotally poor coding of attendance episodes, all attendances were included and no connection made between A&E attendance and subsequent hospital admission)

This data entered the study database, using Microsoft Excel and was analysed as described 7.4.3.

7.4.2.2 Phase 2 Sample B: Survey of adults with T1DM

The survey questionnaire is shown in Appendix G. It collected self-reported data about the person and their diabetes, as well as using validated scores (permission sought to use these where necessary). It was divided into eight sections with reasons for choice of question and further information about validated scores outlined below (7.4.3.2).

1. Knowledge of structured education including three free text questions about the barriers or motivators to attendance at SE.
2. Assessment of health literacy and numeracy using:
    i. Subjective Numeracy Score (SNS) – This uses respondent's self-evaluation of numerical skills and preferences. There are multiple numeracy scores available, however this one was chosen as it was felt that one's personal confidence in ability is more likely to affect attendance at DAFNE than actual ability (Fagerlin et al., 2007).
    ii. Health literacy - One question assessing confidence in completing medical forms

3. Diabetes control & complications
    a. Service use to assess differences in service use for health economic purposes, but also to assess proportion of respondents solely cared for in primary care and the potential to use primary care to engage individuals with SE.
    b. Glycaemic control: HbA1c reported in DCCT % and mmol/mol, unless categorised to QOF targets where it is reported to DCCT % only (<7.5%, 7.5-9%, >9% equivalent to <59mmol/mol, 64-75mmol/mol and >75 mmol/mol). Hypoglycaemia awareness measured using the Gold score (Geddes et al., 2007).
4. Demographic and socioeconomic information including ethnicity, educational attainment, employment status and English language ability. These questions were chosen as previous research found these to be barriers to self-care or attendance at SE for other LTCs. Early findings from P1 influenced variables included in this section.
5. Depression using:
    a. The Patient Health Questionnaire (PHQ) which has been designed to identify people with depression. There are scores of varying lengths, with differing sensitivity according to the number of questions. The PHQ-2 screens for depression (Li et al., 2007, Maurer, 2012). Participants screening positive for potential depression were invited to complete the PHQ-9, a more sensitive tool for identifying at least moderate depression (Kroenke et al., 2001). There is evidence that psychological markers improve with DAFNE but I hypothesised that a difference in psychological scores existed between the attenders and non-attenders influencing their decision to attend, either that their level of apathy associated with depression was preventing them, or that those attending are motivated by their depression or psychological burden of diabetes.
    b. Individuals currently receiving treatment for depression (either medication or therapy) were advised not to complete the PHQ-2 and PHQ-9.
6. Emotional distress using:
    a. Problem Areas In Diabetes (PAID)-5 uses only five questions, reducing participant burden (Snoek et al., 2000). I wanted to measure psychological distress as I felt this might influence decisions to attend (as discussed above).
7. Self-efficacy using:
    a. Confidence In Diabetes Self-care Scale (CIDS) (Van Der Ven et al., 2003).
8. Quality of life section using:

a. Quality of Life was measured using the EQ5D-3L thermometer and the Stanford Social Role/Activities Limitations Score (SSRAL) (Roy et al., 2012, Lorig, 1996).

Although my project poses little risk to participants, there were some ethical considerations. To encourage honesty, participants were informed that responses would not routinely be shared with their HCP. However, if a PHQ-9 response indicated high risk of depression (score >10), I contacted the participant, acting in my clinical capacity. Their score was discussed, with consent and where clinically relevant I sent a letter to their primary care provider, alerting them of the result. Participants of both paper and online surveys could opt out of completing the PHQ-2 or 9 and/or not consent to contact with the research team should their score be elevated.

Severe hypoglycaemia, where third party assistance is required, can be an indication for removal of a person's driving licence (Griffith, 2016). To avoid incomplete or false responses I asked about any hypoglycaemia events (of any severity) in the preceding twelve months but included the Gold score to assess hypoglycaemia awareness.

7.4.2.3 Phase 2 Sample C: Healthcare professional survey

The HCP (Sample C) survey (shown in the Appendix H) included questions about:

- Clinical experience; to assess diversity of responses and generalisability to wider population
- Previous experience of DAFNE including observation or teaching on the course; to assess the influence of this experience on other variables, as well as providing a means to measure selection bias. I anticipated selection bias of clinicians involved with DAFNE as they would be more passionate about the course, and more engaged with research associated with SE.
- Clinician's perception of number of people within their clinic attending/referred/declined/not-suitable for DAFNE.
- Perceived importance of SE (measured on a Likert-type scale 0-10)
- Perceived effectiveness of DAFNE at providing skills to self-manage (measured on a Likert-type scale 0-10)
- Open answer response about perceived barriers to attendance
- Ideas for improvement of the current programme to better suit their local patient population
- An extract from the Diabetes Attitudes Score (DAS) felt to be relevant to T1DM care (Anderson et al., 1998). I wanted to use a validated score to assess the HCPs perception of patient autonomy, burden of diabetes and seriousness of the disease. The DAS measures

these constructs, but is burdensome (with 33 questions) and not all appeared relevant to T1DM. I therefore used a selection of these.

7.4.3 Analysis

7.4.3.1 Sample A

The KHP database was divided per attendance or not at DAFNE. Comparison was made between attender and non-attender groups using univariate and multivariate analysis as described below (7.4.3.4).

7.4.3.2 Sample B

Validated scores used in the survey were calculated and analysed as per original validation studies.

- Subjective Numeracy Score (SNS) used eight questions, scored from one to six. The mean average of these eight questions provides the overall SNS, but can be divided into numerical ability and preference (Fagerlin et al., 2007). Missing data was dealt with using the medical outcome scoring technique (Van Der Ven et al., 2003). If more than half of the questions were unanswered, the SNS was coded as missing.
- Health literacy screening question used a Likert-type scale from one to five, with three being the cut-off for insufficient literacy (Bass et al., 2003).
- The Gold score measured awareness of hypoglycaemia from one to seven, with four or more taken as the cut-off for impaired awareness of hypoglycaemic (Geddes et al., 2007).
- The PHQ-2 used two questions, scored from zero to three, to screen for depression. The answers were added together, with a score above two suggesting high-risk of moderate depression (Li et al., 2007, Maurer, 2012). Participants scoring above two were invited to complete PHQ-9 (Li et al., 2007, Kroenke et al., 2001). The nine-question PHQ-9 (including two from the PHQ-2) was scored from zero to three (total twenty-seven), with a score above ten confirming moderate to high risk of depression.
- PAID-5 used five Likert-type scaled questions, from zero to four. The PAID5-5 was scored as per validation article; with answers totalled and then multiplied by 1.25 (McGuire et al., 2010, Snoek et al., 2000).
- CIDS used twenty Likert-type scaled questions to assess confidence in self-care ability (Van Der Ven et al., 2003). Higher scores were indicative of higher self-efficacy. Missing responses were dealt with using the medical outcome scoring technique and where more than ten

- EQ5D-3L thermometer asked respondents to score their current health state from zero to 100 (Roy et al., 2012). The Stanford Social Role/Activities Limitations Score (SSRAL) used the sum of four Likert-type scale questions (Lorig, 1996).

Online and paper survey responses were combined in a study database using Microsoft Excel. Duplicate responses, identified by study number or email address (where provided), were excluded, with the most complete response kept for analysis. Participants unaware of their type of diabetes had their answers scrutinised and were excluded from analysis if using medication associated with a diagnosis of T2DM. Participants who completed less than half of the first two sections were also excluded. Incomplete answers were coded as missing, unless there was a question that could have a 'nil' answer. In this case, if the respondent had completed the questions either side then a 'nil' response was assumed rather than missing data e.g. complications questions gave options for ticking relevant complications but no option for 'nil/no complications'.

Descriptive statistics compared the demography of respondents to non-respondents from the DECS database. This enabled assessment of response bias and therefore validity and generalisability of conclusions drawn. The P2 survey database was analysed using both univariate and multivariate analysis as described below (7.4.3.3 & 7.4.3.4).

7.4.3.3 Univariate Analysis

Data was analysed using SPSS (IBM SPSS Statistics version 22).

P1 and P2 were analysed separately but used similar statistical methods. They were analysed according to attendance or not at SE (attender or non-attender). Those who had attended but not completed SE were classified as non-attenders. Demographics of attenders and non-attenders at SE were compared using descriptive statistics. Data was checked for normal distribution, which influenced test used: Not normally distributed data were presented as medians with inter-quartile ranges; however means were also presented for illustrative purposes. Normally distributed data were presented as means with standard deviation. Statistical significance was measured using unpaired 2-sided t-tests for normally distributed data and non-parametric tests for not-normally distributed data; Mann-Whitney U if two groups or Kruskal-Wallis test if more than two groups (Petrie and Sabin, 2013). Categorical data were represented as count and percentage and Chi-squared tests used to compare groups (Petrie and Sabin, 2013).

Categorisation for P2 data was necessary to make some responses more clinically meaningful or to analyse them in a more appropriate way. Categorisation included:

- *Depression* was categorised to include people with PHQ2 above two, or currently undergoing treatment for depression. Participants with missing answers were coded as missing unless one of the variables was positive (PHQ2 was used rather than PHQ9 to minimise missing data).
- *Medication* was categorised per regimen e.g. multiple daily injection (MDI) with once or twice daily background insulin; premix insulin or CSII.
- *Service use* was calculated for the previous twelve months and analysed according to; total use of all NHS services, total visits and total contacts (email or telephone) plus use of secondary care as a binary ((yes or no) if at least one visit to a diabetes doctor or nurse in the hospital or a dietitian) and use of specialist community care as a binary variable (yes or no).
- *Diabetes-related complications* were calculated as a total number of complications listed by respondents and as a binary variable by presence or absence.
- *Problematic hypoglycaemia* was a composite binary variable consisting of hypoglycaemia events and Gold score. It was calculated according to risk of problematic hypoglycaemia based on presence of hypoglycaemia events in the preceding year and a Gold score of more than four (indicating impaired awareness). If data for hypoglycaemic events were missing but impaired awareness was indicated on Gold score this was categorised as problematic, however if hypoglycaemic events were reported but Gold score was not completed then this was coded as missing data. It was scored in this way to increase the sensitivity to risk of severe or problematic hypoglycaemia.
- *Glycaemic control* was categorised according to current QOF cut-offs (NHS England, 2014). An additional category existed for those with no knowledge of their HbA1c.
- *Benefit* was a composite of glycaemic control and risk of *problematic hypoglycaemia* (as above). There were three groups; those with HbA1c below 7.5% and no problematic hypoglycaemia, those with either HbA1c above 7.5% and/or problematic hypoglycaemia, those with no HbA1c knowledge and no problematic hypoglycaemia. This categorisation enabled assessment of the proportion of respondents with little potential benefit from DAFNE due to adequate glycaemic control in the absence of problematic hypoglycaemia.

7.4.3.4 Exploratory Multivariate Analysis

An exploratory multivariate analysis (binary logistic regression model) looked for associations between measured variables and attendance at SE in both P1 and P2.

Variables were included if they had been significantly different in the univariate analysis. Additional variables, likely to be influential based on previous research, were also included. A p-value of less than 0.2 was considered significant for inclusion in P2 multivariate analysis. Due to the exploratory nature of P2 and the vast number of variables measured co-linearity between variables was checked prior to inclusion in the model. If two variables had a correlation coefficient >0.4 one was excluded, with preference given to the variable with greater statistical significance in univariate analysis.

Data with more than 30 missing variables were categorised (including a 'missing' category) to enable inclusion in the regression analysis. Where possible categorical variables with multiple categories were re-categorised to a smaller number, as is best practice for multivariate modelling. A forward Wald analysis was used, with backward Wald analysis as a sensitivity analysis, to check that similar variables were found to be significantly associated with attendance. This was done both with and without categorisation (missing data removed) to ensure validity of results and no undue consequences of categorisation. Model goodness of fit was checked with Hosmer & Lemeshow test, whilst variance was calculated with both Cox & Snell R^2 and Nagelkerke R^2 (Petrie and Sabin, 2013).

7.4.3.5 Subset Analysis

Subset analyses were carried out on P1 and P2 data. Descriptive statistics were used as described above (7.4.3.3). Categorisation of variables was necessary, to overcome missing data, which is described in associated chapters. The subset analyses were:

- In P1 the subset was based on non-attender ethnicity. The diversity of the local population provided sufficient sample size of minority ethnic groups to do this.
- In P2 variables associated with attendance at DAFNE in the regression model were further investigated. This iterative subset analysis only included non-attenders. Bonferonni correction was made to the level of critical significance, considering the multiple tests used in this exploratory analysis (Bland and Altman, 1995).

7.4.3.6 Coding of open question responses

Responses to open questions about barriers or motivators to attendance at SE in the Sample B survey were analysed using qualitative techniques with codes being converted or 'quantisised' into numerical data for further analysis. Responses were analysed following a nine-step procedure detailed in Table 7-1 (Forbes et al., 2007, Feher Waltz C. et al., 1991). Coding of the open responses was an inductive iterative process, led by the data rather than theory.

Table 7-1: Nine step procedure for analysing open question survey responses.
The table illustrates the nine steps within the context of the BUDiE study. Adapted from Feher Waltz et al. (1991).

Step	The BUDiE study
1. Define the universe of content to be examined.	The universe of content was: all relevant responses generated by the item. Relevance was determined by the presentation of a clearly identifiable barrier/enabler.
2. Identify the characteristics or concepts to be measured.	The concept requested from the data: What do you think is the ONE biggest thing preventing you from coming to a self-management course? What do you think is the ONE biggest thing that would make it easier for you/encourage you to attend? What was the ONE most important thing that encouraged you to attend DAFNE or similar self-management courses? The first identifiable barrier or motivator given was taken as the answer. Ambiguous answers were reviewed in context of surrounding answers, and where they remained ambiguous they were coded as miscellaneous.
3. Select the unit of analysis to be employed.	The primary units of analysis were codes; labels that describe the content of the response.
4. Develop a sampling plan.	All relevant responses were analysed.
5. Develop a scheme for categorising the content.	The data were coded both deductively and inductively. Each response was coded based on the substantive proposition articulated. Once coded, overarching themes were identified based on shared or common characteristics.
6. Develop explicit coding and scoring instructions.	Initially two researchers independently reviewed the responses and generated prototype codes. These were discussed among the researcher group until agreement was achieved over each code. This resulted in the production of a coding matrix.
7. Pretest the categories and coding instructions.	Two people, including a service user, originally involved in production of the coding matrix coded a sample of 25 raw data. This iterative production of the coding matrix continued until >70% inter-rater correlation.
8. Train coders and establish an acceptable level of reliability.	Three researchers, including a service user, independently coded the data. Where ≥2/3 codes agreed, the code was used. However, where each researcher had assigned a different code a further member of the research team reviewed these disagreements and agreed codes.
9. Perform the analysis.	The coding matrix was used to code all relevant data as described. These codes were entered into SPSS for further quantitative analysis.

The coding matrix was designed in this manner for the first open question in the survey '*What do you think is the ONE biggest thing preventing you from coming to a self-management course?*'. Once this matrix had been refined it was used for the remainder of the open question responses, including those in the healthcare professional survey. Further refinement was required to ensure the original matrix fit the data, however I wanted to maintain coding similarity to allow comparison of the open question responses between non-attenders and their HCPs.

Sample C survey contained four open questions, with two coded as described in Table 7-1. There were six open questions in Sample B survey with respondents being directed to part A or B according to previous attendance at SE. Three questions were compulsory and formally coded as described above (Table 7-1). Additional responses were analysed using word frequency analysis in NVivo 11. Word frequency analysis assesses the number of times a word occurs, and converts this to a pictogram to visually represent frequency as size of the word. Data for motivators or enablers were combined and entered the analysis, with words less than three letters excluded and truncation accounted for. This technique enabled recognition of additional themes that had not been identified through the manual coding process, and provided visual representation of responses in order to sense check the coding matrix (Stemler, 2001, Ryan and Bernard, 2003).

7.5 Qualitative Methods

Qualitative data allows a much deeper investigation of reasons for non-attendance at SE. There were two data sources:

- Semi-structured interviews
- Focus groups

7.5.1 Design

7.5.1.1 Semi-structured interviews

Semi-structured interviews were conducted with people who had not completed SE. Power calculations were not performed, as I was not trying to reach statistical significance, but reach thematic saturation. (Ryan and Bernard, 2003). Sufficient numbers were required to enable comparison across groups and proportionate stratified sampling was used, according to ethnicity, age and gender (Joffe, 2011). Interviewees were asked for their HbA1c as a surrogate marker for diabetes self-care abilities and indication of potential selection bias. P1 results defined the purposive sampling matrix from which potential participants (from the P2 Sample B cohort) were invited at random. Interviewees received a separate information leaflet and written consent was taken prior to commencing the interview process.

The topic guide (Appendix I) was informed by preliminary themes arising in the open question responses from the survey. It was also influenced by previous research into barriers to self-care in long-term conditions (see 6.4), clinical experience and the advisory group's personal experiences.

The advisory group was invited to comment on the topic guide, reflect on language used and pilot the interview.

Interviews lasted between 60-90 minutes. They were held at a date and time that suited the participant (including out-of-hours) and where possible, co-ordinated with outpatient clinics to minimise inconvenience. I conducted all interviews. Participants who had never heard of DAFNE were given a brief outline, based on my experience and knowledge of the course, and continued to be interviewed regarding the likelihood of them attending and their opinions. My PhD supervisor (HM) reviewed a selection of early interviews to certify methodology and study robustness.

7.5.1.2 Focus Groups

The data generated from focus groups were very different from one-to-one interviews, because they were generated by the interaction of the group (Ritchie et al., 2013). The questioning within the group and reflecting upon their own experiences created a more refined and considered individual response. This synergism within the group created rich data and I simply facilitated the conversation, rather than interviewing individuals (Ritchie et al., 2013). Focus groups are thought to offer a more natural environment for sharing and shaping ideas and concepts, although shared assumptions may expunge elaboration as they are taken at face value (Ritchie et al., 2013). Participants influence each other, social norms appear and the group can generate more realistic data. Therefore, a focus group provided opportunity to bring together people with shared interests but heterogeneous experiences or backgrounds to develop recommendations and expand on findings from the earlier parts of my study (Ritchie et al., 2013). I utilised participatory research methods throughout the focus groups to test early findings, seeing if they rang true with other service users and professionals, discussing plausible solutions and considering feasibility in the current health ecosystem.

To achieve the above I invited different stakeholders to enable sharing of experiences and to allow the group dynamic to question social constructs of individual participants. For example, bringing together a commissioner who is involved in strategic decision making for multiple LTCs, with a provider of diabetes SE may prompt both to reflect on their current priorities, prejudices and preconceived ideas about diabetes and SE. I did not use proportionate representation but purposive sampling to collect a wide range of opinions from different backgrounds; gender, age, ethnicity and attendance at SE.

When constructing a focus group, it is important to allow all voices to be heard, ensuring that

therefore held five focus groups made up of different proportions of service users, service providers, commissioners and other people involved in strategic decision making in diabetes SE. Some of the groups only involved service users, where there was a mixture of those who had and had not attended SE. One focus group with professionals involved in diabetes care included service users. Richie et al. suggest at least three people representing each group to avoid tokenism but appreciate that this may not be possible in reality (Ritchie et al., 2013). To overcome potential hierarchical dominance participants perceived to be self-assured within this environment were invited. Another focus group was made up of professionals involved in diabetes care around South London, but not Southwark and Lambeth. This ensured generalisability of results into other locations where DAFNE may not be the provided SE programme and/or SE is not as firmly embedded into the psyche of HCPs.

Each focus group had between four to ten participants. I facilitated all groups with additional support from fellow researchers. A service user (AM), recruited from the study advisory group, observed one or two groups. He made notes on key emergent themes and had an opportunity to ask additional questions before the close of the group, but did not formally participate.

The topic guides for the focus groups were based upon P1 and P2 research findings, and reviewed by peers and the advisory group prior to use. There were two topic guides (Appendix I); one presented early research findings, checking interpretation was grounded in users' experiences and generating broad debate around potential solutions. The other was directed at specific solutions generated from the early analysis of P1 and P2. It honed in on details associated with these solutions, looking at feasibility issues such as time and financial resource, as well as other factors influencing implementation and uptake.

7.5.1.3 Interviews & Focus Groups

Interviews and focus groups were face-to-face and held in clinical or academic facilities across south London. I took written consent from all participants. Participants were aware that their contribution was confidential and that they had the right to terminate the discussion at any point. Any dialogue terminating prematurely could be used and analysed up to the point of termination, with the participant's consent. Focus group participants were aware that other people would be present and that they divulged personal and therefore identifiable information at their own discretion. They were invited to use a pseudonym or study number if they preferred. Interviews and focus groups were audio-recorded and transcribed verbatim to Microsoft Word documents. Unique study

conversation was anonymised on the transcript, for example names of doctors. Participants had a case report form containing their study number, demographic and biometric data (where relevant). This form was kept in a secure location, separately from the research data. Transcripts were stored and managed by qualitative comparison software, Nvivo 11.

7.5.2 Thematic Framework analysis

Qualitative research uses a naturalistic interpretative approach that is concerned with exploring phenomena from the interior (Ritchie et al., 2013). It uses flexible design and analysis, responding to new concepts as they arise in an iterative manner. Hypotheses are often generated by the data, rather than a priori. The central function of qualitative research is discovery of themes. Themes describe a 'specific pattern of meaning found in the data' (Joffe, 2011). These themes are often identified before, during and after data collection (Ryan and Bernard, 2003). Themes may come from latent or manifest content, so are either explicit or implicit. Often they are abstracted to high-order themes or categories.

I chose a thematic framework analysis approach using both deductive and inductive strategies (Ritchie et al., 2013). A pragmatic approach was required, choosing the appropriate tools to answer the research questions, rather than adhering to only one method. To accommodate the interaction between myself and participants, I used reflexivity to maintain empathic neutrality and transparency, recognising the effect of interactions and being plain about assumptions and potential bias (Ritchie et al., 2013).

Thematic analysis involves 'discovering, interpreting and reporting patterns and clusters of meaning within data' (Ritchie et al., 2013). 'It facilitates the gleaning of knowledge of the meaning made of the phenomenon under study by the groups studied and provides necessary groundwork for establishing valid models of human thinking, feeling and behaviour' (Joffe, 2011). Thematic coding forms the backbone of many research methods. I worked systematically through the data to identify topics that progressively became higher order key themes. More than twelve different methods for identifying themes have been described, varying from counting frequency of recurring words through to linguistic approaches such as looking at metaphor and analogy use (Ryan and Bernard, 2003). Two techniques used in this study were 'pawing' and 'cutting and sorting'. Pawing is like the familiarisation phase in thematic framework analysis, as it involved immersing myself in the text, ocular scanning, and marking key phrases (Ryan and Bernard, 2003). Second, cutting and sorting is like the technique required for indexing and sorting. This involved breaking the data down into

thematic categories (Ryan and Bernard, 2003). These techniques can be combined in a sequential manner to provide a more powerful strategy.

I chose thematic framework analysis because it combines these techniques in a systematic, transparent and tried and tested way without sacrificing depth of analysis, making it easier to follow as a novice researcher (Joffe, 2011). Additionally, it is not tied to any particular disciplines or set of theoretical constructs (Joffe, 2011). I used it in my study as an approach in its own right; using framework thematic analysis as described by the NatCen group in the 1980's (Ritchie et al., 2013). This has distinct phases making it more transparent and robust than other qualitative methods (Furber, 2010).

I used a substantive approach, allowing capture and interpretation of meanings within the data, rather than interpreting the use of language and structure of interview. The cross-sectional method meant that codes were created to fit all data. Initially these were labels that allowed data to be ordered systematically, searched and retrieved by label and grouped similar categories together to allow comparison. Thematic analysis allowed multiple codes for the same data excerpt (Joffe, 2011). Through higher-level analysis I refined these into more abstract themes, which were applied to data extracts (Ritchie et al., 2013). This process moved through three phases; organising, describing and explaining and is defined in more detail in Table 7-2 .

Table 7-2: Table illustrating the stages required for thematic framework analysis taken from Ritchie et al (Ritchie et al., 2013).

Data management	Abstraction & Interpretation
Data familiarisation **- Read all transcripts/text**	Finding themes & concepts - Analyse each set of themes to identify range of perceptions/views - List the elements present - Define key dimensions that differentiate each element - Iterative process moving between abstract concepts and data extracts
Produce a thematic framework based on clinical experience, published research and familiarisation with interviews **- Usually 5-7 themes** **- Hierarchical themes and subthemes** **- Descriptive labels to allow sorting rather than abstract that may distract.**	Identifying linkages - Group similar types of dimensions together - Consider how the data interacts - Look for associations or connections to form overarching 'higher-order' classifications - Typologies may become evident at this point - Look for linkages between phenomena, this may be functional, structural, contextual or sequential. E.g. beliefs leading to certain behaviours
Index and sort **- Label data to fit the framework** **- Sort data according to label, so as to reassemble 'fractured discourse' (where topic has been discussed multiple times at different points in the text.**	Interrogating for patterns or meanings - Use retroductive logic to find explanations for the data - Look for explicit and implicit inferences from the data - Try to make logical sense of patterns or fitting to existing theory
Summarise data from each case into each label **- Use phrases/expressions from participants own language** **- Minimise interpretation** **- Do not necessarily dismiss data where reason for inclusion is not immediately obvious**	

Not all the above steps were required; as I used semi-structured interviews my data was sorted to a degree due to the nature of the topic guide. Summarising data can be done either theme-by-theme or case-by-case. I summarised theme-by theme, the advantage being that complete immersion into the theme allowed a more refined understanding of content and variation.

One of the key advantages of thematic analysis is its ease of use with multiple researchers. In my study a service user was involved in the iterative creation of the coding matrix and analysing a proportion of interview transcripts. After I had created a coding matrix the service user (AM) coded 10-20% of the data. We reviewed the correspondence of code application, any idiosyncrasy was discussed, and the matrix was either refined or a new frame produced.

Similar qualitative analysis was used for the focus group data; with data being coded using Nvivo 11, and higher-level themes being identified.

Qualitative research requires iterative changes and these are outlined in the results chapters for each phase, along with any changes made to the recruitment process.

Literature reviews are important to understand the current evidence and recognise any existing gaps. As my background reading had highlighted numeracy and health literacy as a potential barrier to self-management in diabetes I wanted to investigate this further. Therefore, I chose this subject for my systematic review, which will be outlined in the following chapter.

8 Does health literacy and numeracy affect self-care in people with type 1 diabetes? A systematic review of the literature.

8.1 Background

Self-efficacy is an important psychological construct associated with self-care abilities. It can be defined as the person's confidence in their ability to perform certain behaviours (Bandura. A, 1977). Self-efficacy is associated with improved self-care in chronic conditions such as asthma and diabetes (Jahanlou and Karami, 2011). Environmental, behavioural and personal factors all affect self-care abilities. Among personal factors, literacy and numeracy skills are extremely important. HCPs rely on adequate patient literacy levels to transfer knowledge about diabetes and self-care. They provide written information about personal insulin doses as well as printed resources containing more general information, relying on the patient being able to use them.

The British 'Skills for Life' survey in 2003 found over half the nation had literacy skills below the level of General Certificate of Secondary Education (GCSE) A-C, and 39,000 people (6%) had less than level 1 English (GCSE D-G equivalent), producing a national average reading age of a 9 year old (Kerr, 2007, The Public Accounts Committee, 2009). Similarly 40-44 million (25%) adults are functionally illiterate in the United States of America (USA) (The Council on Scientific Affairs, 1999). Functional literacy is context specific; functional health literacy describes the ability to function in the healthcare environment and is distinct from literacy, as the person may struggle to understand due to unfamiliar vocabulary and concepts specific to the setting (The Council on Scientific Affairs, 1999, Schillinger et al., 2002). For example, 60% of patients are unable to understand a standard consent form (Williams et al., 1995). Despite this, the healthcare system still relies heavily on written material to inform their patients. These materials are commonly rated as readability level 'difficult' (30-50 Flesch-reading ease), equivalent to the reading age of a 15 to 17 year old, at least six years above national average capability (Kerr, 2007). People with adequate literacy skills are able to build on the information gained from their HCP by using the internet, where there are multiple blogs, forums and information sites with average reading age of 14 years (Boulos, 2005). A person's functional illiteracy excludes them from these sources, preventing them from learning more about managing their condition, reducing their health literacy and self-efficacy.

Low health literacy is common in Type 2 diabetes and has been linked with reduced diabetes knowledge and understanding of diabetes self-management, as well as adverse clinical outcomes

literacy is associated with double the rate of hospitalisation with only 50% of people with inadequate health literacy correctly identifying the symptoms of hypoglycaemia, compared to 94% of patients with adequate literacy (Weiss et al., 1992, Baker et al., 1998, Parker et al., 1995).

Inadequate numeracy (ability to use numbers in daily life) affects 75% of the UK working population (less than GCSE A-C) and 60% of the USA population (Cavanaugh, 2009, The Public Accounts Committee, 2009). Health-related numeracy, like health literacy, requires additional skills to function in the healthcare system, such as interpreting risk, multistep operations and identifying appropriate use of skill mix (Cavanaugh et al., 2008). Effective intensive insulin therapy involves a multi-step numerical process (Kerr and Marden, 2010). First, measuring plasma glucose and interpreting the glucometer result, a task that a quarter of people with T2DM cannot perform (Cavanaugh et al., 2008), second, calculating the carbohydrate content of a meal. And lastly, calculating insulin dosage; which relies on completing the first two tasks plus consideration of insulin ratios and correction doses. This complex numerical task involves the combination of several skills including division, converting units and multiplication of decimals to produce an end insulin dose that only 40% of people can do (Cavanaugh et al., 2008). Analysis of the information provided to people living with T1DM shows the content of an insulin dose adjustment task to be equivalent to GCSE grade A*-C level, with some parts being level 3 numeracy skill, the equivalent to A-level (Kerr and Marden, 2010). Unlike T2DM, which is associated with lower level of educational attainment (Sacerdote et al., 2012, Dupre et al., 2015), T1DM affects a cross-section of society. There are therefore people possessing the skill mix necessary to digest written and numerical information, and make informed decisions about their daily self-care. Equally there are others without higher level mathematics skills who struggle with these daily diabetes self-care decisions, for example by using fewer of the features on an insulin pump on a regular basis (Kerr et al., 2008, Patrakeeva et al., 2013). This does not allow them to benefit fully from the potential advantages bestowed by technological advances in insulin delivery methods (Kerr and Marden, 2010).

Clinically, there may be clues as to someone's numerical ability. For example, people with lower levels of numeracy leave school at an earlier age and have a higher level of unemployment (Grinyer, 2006). However educational attainment and general literacy are insufficient measures of health literacy or numeracy and validated scores are needed (Rothman et al., 2006). A recent systematic review identified nine health literacy and three numeracy scores (Al Sayah et al., 2013). The short Test Of Functional Health Literacy in Adults (sTOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM) are most commonly used, having been validated in different languages and

exists; the Diabetes Numeracy Test (DNT). Other numeracy scores exist such as the Newest Vital Signs (NVS) which uses six questions to assess ability to read food packets, or the subjective numeracy score which asks for an individual's opinion on their ability and preferences (Khazaezadeh et al., 2012) . Due to the nebulous definitions of health literacy and numeracy, and their underlying components (functional, interactive, critical and numeracy skills), there is no agreed gold standard scoring system (Al Sayah et al., 2013). This makes validation awkward. Newer literacy and numeracy scores have all been validated against REALM or TOFHLA, despite some of them testing components underrepresented in those systems (Al Sayad et al., 2012).

Despite increasing interest in health literacy and numeracy and their influence on self-care of chronic conditions, there is little evidence for their impact in T1DM. T1DM is the exemplar of chronic conditions requiring high level of numerical skills with easily measurable surrogate end points for ability to self-care. This literature review will examine existing research to investigate the influence of health literacy and numeracy on self-care behaviours in T1DM.

8.2 Rationale for the Research Question and Method

Data collection is both time and economically costly. A literature review allows me to explore a predefined research question in a resource-efficient way (Aveyard, 2007). Results extrapolated from other studies can be brought together to produce a larger sample size and more robust data. With increasing numbers of monthly publications, both in press and online, a literature review can bring the evidence together in a systematic way to summarise and interpret the results, producing a stronger evidence-base for clinical practice. Systematic reviews ensure the literature is searched in a comprehensive manner with a transparent protocol, so that it can be repeated and validated by independent researchers. For these reasons, I have used systematic review methods to review the evidence for the effect of health literacy and numeracy on self-care processes in adults with T1DM. In addition to the above advantages, a systematic review adds to the project thesis as the cross-sectional study component of this project includes measures of numeracy and health literacy. Reviewing the evidence from other populations with different demographics allows analysis of the effect both locally and globally.

A PICO (Population, Intervention, Control, Outcome) approach was used (Huang et al., 2006). The population to be studied was adults (18 years or older) with T1DM. Studies with children were excluded as they have not yet completed their education, and therefore are likely to have a lower level of numeracy and in general are not self-caring. Their carers or parents were also excluded, as

was mixed (T1DM and T2DM or children and adults) the study was included if more than 70% participants met the inclusion criteria, or the results could be extrapolated for this group. Studies with less than 20 people with T1DM were excluded, based on power calculations finding sample size over 100 necessary to achieve a medium sized effect with 0.8 power (Zaugg et al., 2014, Marden et al., 2012).

The level of numeracy or health literacy (adequate versus inadequate) was the intervention studied. Only validated scores were included, whilst assessment of educational attainment or profession was excluded as their association with numeracy is unclear (Piatt et al., 2014). Additionally, educational standards vary globally making it difficult to compare educational attainment across studies. Educational attainment is often based on graduation from a compulsory education system into voluntary. For example, compulsory schooling ends at age sixteen in the UK with a General Certificate of Secondary Education (GCSE) examination (Wikipedia, 2015). In the USA 9^{th} grade, which marks this transition, falls between fourteen to fifteen years old.

To enable comparison of studies using different scores, the initial score validation study was read and the score extrapolated and converted to one universal score, such as REALM. If this was not possible, the scores were converted to equivalent educational attainment level. USA 9^{th} grade was considered equivalent to UK level 1 (GCSE C).

The outcome assessed included any form of self-care, for example; attendance at clinic, vaccination rate, glycaemic control or daily foot check. Glycaemic control is usually measured by a surrogate marker; HbA1c. HbA1c does not have a normal distribution and this is often dealt with using a log normal calculation, with the values often being reported as a median with interquartile ranges. Where there was a difference in reporting, the Hozo formula was used to convert median and range into mean with standard deviation to enable comparison (Hozo et al., 2005).

There is a complex relationship between education, diabetes knowledge and self-care. Lower health literacy is linked to diabetes knowledge and lower self-efficacy (Fransen et al., 2015). Diabetes education increases knowledge; however health literacy may underpin the value of this education for individuals with low health literacy. Therefore, to enable exploration of the direct relationship between health literacy and self-care, diabetes knowledge was not included as either a measure of health literacy or an outcome.

The reasons for these strict inclusion and exclusion criteria have been outlined but they mean that

sufficient power, which will make analysis more difficult and may affect the possibility of reaching a firm conclusion.

8.3 Methods

The systematic review was registered on PROSPERO (protocol number 42015014278)(PROSPERO). The search criteria were produced in an iterative manner. Initial searches based on previous Cochrane Collaborative search terms identified appropriate articles (Hawthorne et al., 2008). The keywords for these were analysed and included in future searches, until the search was felt to be comprehensive. The search was limited to English language articles only.

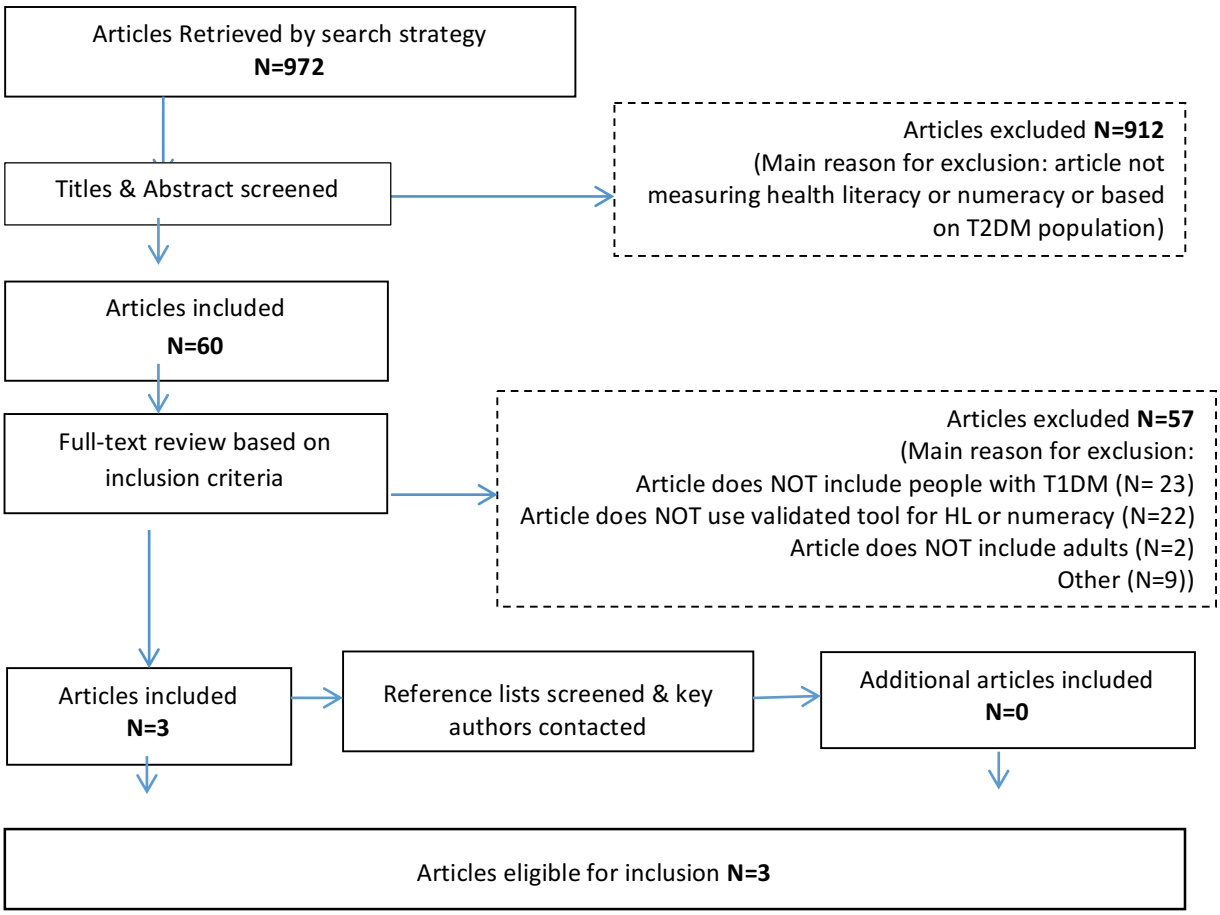
A medical student (PM) and I (SH) independently searched the four databases most relevant to the research question using the search criteria in Appendix B. Medical Literature Analysis and Retrieval System Online (MEDLINE), PsycINFO, Excerpta Medica dataBASE (EMBASE) and Health Management Information Consortium (HMIC) were searched from inception until October 2015. Articles that were not primary source were excluded. Conference papers were included and authors contacted to provide further information where possible. Authors that did not clearly describe their study population or did not present separate results for participants meeting my inclusion criteria were contacted for additional information or to extrapolate relevant data where possible.

All titles of articles were read; non-relevant articles and duplicates were removed. Remaining article abstracts were then read and potentially relevant articles retrieved and reviewed in full. Those not meeting the inclusion criteria on reading of full article were discarded (Figure 8-1). Any disagreements were discussed with my supervisor (HM). All studies meeting the inclusion criteria were hand-searched for additional relevant articles, which were read to assess whether they met the inclusion criteria. Authors of included studies and experts in the field were contacted to recommend further articles or provide information about on-going work (Greenhalgh and Peacock, 2005).

In order to provide consistent appraisal style and reduce likelihood of researcher bias articles meeting the inclusion criteria were assessed using the critical appraisal skills programme (CASP) tool (Critical Appraisal Skills Programme (CASP), 2013, Aveyard, 2007). The methods relied on electronic searches, which may miss some references, and there may be publication bias affecting the result, reference lists of included studies were searched and experts in the field contacted to overcome this (Easterbrook et al., 1991, Greenhalgh and Peacock, 2005).

Due to the numerous ways to measure health literacy and numeracy, and the lack of gold standard measure, the validation papers for each score were read to find a universal equivalent score to enable comparison (Al Sayah et al., 2013). Ideally meta-analysis would have been used if more than three studies were included in the review, where a universal score could not be found or meta-analysis was not possible a narrative synthesis would be used to describe the studies and their evidence.

Figure 8-1: PRISMA diagram of inclusion and exclusion process.
This flow chart is modified from http://www.prisma-statement.org and it shows the study identification and selection process



8.4 Results

972 studies were identified by the search, but only 3 met the inclusion criteria for review (see Figure 8-1 and Appendix C). Table 8-1 presents a summary of the design and results of each

8.4.1 Study designs

All three studies used English speaking adults (18-65 years old) with at least one year of diagnosis from USA and UK. The USA based studies recruited participants from across primary and specialist care, and included a mixed population of both T1DM and T2DM. The UK based study recruited individuals with T1DM only from specialist care.

All three studies used a cross-sectional survey design, meaning that association but not causation can be interpreted. Response rates varied from 17 - 64% with sample sizes ranging from 112 to 398 participants (mean 234 participants). All study surveys collected demographic and diabetes specific measures, as well as formally assessing numeracy and/or literacy levels. One study used the UK Skills for Life (SfL) assessment tool, a score used within the British education system but not validated for use in healthcare. The other studies used a diabetes specific measure of numeracy and health literacy, the Diabetes Numeracy Test (DNT). Other measures, REALM and Wide Range Achievement Test (WRAT), were also used in one study. All studies used these scores to determine the influence of health literacy and numeracy on diabetes outcomes, using recent HbA1c (within 3 -6 months of study). All of the studies used multivariate modelling to adjust for covariates such as age, sex, and type of diabetes.

The identification of only three studies and the use of different scoring systems between studies made narrative synthesis the optimal analytic tool (Popay et al., 2006). Six main themes were highlighted:

- Measures of numeracy and health literacy
- Numeracy and glycaemic control
- Numeracy and diabetes type
- Numeracy and self-care
- Literacy and glycaemic control
- The impact of socio-economic factors

Study	Ethics & funding	Population	Design & Allocation	Variables	Analysis	Results	Conclusion	Limitations/Critique
S. Marden et al. 'Poor numeracy skills are associated with glycaemic control in Type 1 diabetes' Diabetic Medicine 29, 662-669 (2012)	Yes; UK No funding mentioned	T1DM attending 2° care clinic, UK; Age 18-65yr; Sample compared to clinic population	Cross-sectional survey; Random number generator; Sample size calculator Stopped recruiting when 112 completed. Identified 650, 112 completed; 17% response rate	UK skills for life (SFL)/adult core curriculum (40 literacy, 25 numeracy measures), 1-2 hrs to complete; One HbA1c within 3 months; Socioeconomic Educational attainment; IMD score; Attendance at structured education	Categorised scores in SFL; Level 1 (L1) or Level 2 (L2) Mean HbA1c; t-test Chi^2 2-sided significance 5% Pearson's linear correlation adjusted for variables	Similar sample vs population characteristics 75% <L2 literacy 47% <L2 numeracy; HbA1c not associated with literacy; Hba1c associated with numeracy, after adjustment; Parsimonious model: HbA1c, age, age left school	Numeracy significantly associated with glycaemic control (after adjusting). When combined with literacy not significant.	Only one measure of HbA1c & not normally distributed so better to have used Spearman Rank. Not a confirmatory study (insufficient power) Selection bias Working population Stigma of low HL Poor control (maybe due to low HL) in older population would lead to illness so under-represented Socioeconomic data based on postcode (IMD) Not generalisable SE attendance 48% (v10%) 48% higher level education Secondary care setting SFL not validated in health care setting/disease specific

Study	Ethics & funding	Population	Design & Allocation	Variables	Analysis	Results	Conclusion	Limitations/Critique
S. Zaugg et al. 'Diabetes Numeracy and Blood Glucose Control: Association with Type of diabetes and source of care' Clinical Diabetes 32(4), 152-157, 2014	Ethics not mentioned Ohio PACE grant	Mixed population (T1& 2 diagnosed >1yr) English speaking 18 yrs or more 1° & 2° care, USA	Cross-sectional survey study Power calculations (128); 194 recruited at clinic appointment No mention of allocation	DNT-15; Demographic (supplemented by records); Disease duration & type; Most recent HbA1c; Care provider	Mean ANCOVA with t-test in post-hoc analysis adjusting for variables; Chi^2 2-sided Significance 5%	Better DNT score for those in 2nd care; Better DNT for higher educational attainment; DNT negative correlated with HbA1c for T1 group (adjusted for other variables)	Numeracy correlated with glycaemic control in T1 DM No discussion about T1 specifically.	Only most recent HbA1c used; Completed DNT in waiting room so may have sought help from others. No comparison to background population; however 34% college graduates >80% received SE Not powered for T1DM (n62); Difficult to adjust for type of DM and place of care (assuming most T1DM attend 2° care); Close cluster in higher DNT score making - possibly less sensitive at this level; Recruitment depends on clinic attendance Don't mention allocation Don't mention response rate DNT 15 not valid in T1 as one question about Metformin;

Study	Ethics & funding	Population	Design & Allocation	Variables	Analysis	Results	Conclusion	Limitations/Critique
K. Cavanaugh et al. 'Association of numeracy and diabetes control' Ann Int Med 2008; 148; 737-746	Yes – Tenessee, USA Funding ADA, Pfizer, Vanderbilt	Mixed (T1&2 >1yr) English speaking 18 – 85 yrs 1° & 2° care, USA Excluded blind/partial sighted/dementia $20 incentive	Cross-sectional study 615 identified; 398 completed; (64% response rate)	Demographics; Treatment Disease duration & type; HbA1c within last 6 months; BMI; REALM WRAT-3 DNT Diabetes knowledge test; Summary of diabetes self-care activities; Perceived diabetes self-management scale	Median & IQR DNT percentage; Quartile of DNT; Cuzick non-parametric test (DNT&HbA1c) REALM & WRAT categorised to 9th grade GLM log-HbA1c & DNT with adjustment	69% <9th grade numeracy; Median HbA1c 7.2% <9th grade literacy equivalent to median 40% DNT <9th grade numeracy equivalent 51% DNT High DNT associated with greater perceived self-efficacy High DNT association with lower HbA1c (non-significant)	HbA1c not associated with general numeracy/literacy Adequate literacy not a marker for numeracy Numeracy maybe more important for T1 10% drop in DNT = 0.09% increase HbA1c	Didn't measure adherence to medication Association and not causation (cross-sectional) Performance on DNT may reflect diabetes knowledge/education/provider management. Caution with subset analysis as not *a priori* and multiple analysis No power calculation Allocation bias Not powered for T1 Validation study Couldn't adjust for education because of co-linearity Not compared to background population

1611 *Table 8-1: Selected characteristics of included studies examining the effect of numeracy and health literacy on self-care in T1DM. 1° care = Primary care (General practice), 2° care = Secondary*
1612 *or Specialist care, GLM = generalised linear model, BMI = Body mass index, HL = health literacy, IMD = index of multiple deprivation, SFL = Skills For Life*

8.4.2 Measures of Numeracy and Health Literacy

The use of different scoring systems made direct comparison difficult. For example, the skills for life score was originally categorised according to Level 2 numeracy. Level 2 numeracy in the British education system is not equivalent to American 9th grade, as it is an above average achievement, achieved at an older age than in the USA system (16 years versus 14 years) (Wikipedia, 2015). This inconsistency of scoring was dealt with by converting DNT scores into quartiles (G1-4), based on reported results of the entire study population. These quartiles were then compared to other validated scores in order to draw direct comparisons across the studies. Fourteen percent of participants achieving >9th grade numeracy on WRAT fell into G1-2 of DNT. Therefore, G1 DNT was considered equivalent to less than 9th grade numeracy and G3 was considered the equivalent of level 2 numeracy in the British education system. Therefore, the Skills for Life scores was tabulated either side of the DNT mean (G2-3) (Table 8-2).

Table 8-2: Results of self-care outcomes according to health literacy or numeracy score extrapolated from all studies included in systematic review. Numeracy and health literacy scores have been categorised by quartiles for the study population and compared to national compulsory educational levels (see text for further explanation). P values shown are taken from primary source, and statistical significance is taken as p<0.05. Italicised mean HbA1c indicates result calculated from reported median.

STUDY Score used Reported p value	Q1	Q2	Q3	Q4
Marden et al. **Skills for life (numeracy)** **p=0.004**		Mean 9.2% +/- 1.7% (77 +/- 18 mmol/mol) n=53	Mean 8.4% +/- 1.2% (68 +/- 13 mmol/mol) n=59	
Zaugg **DNT15**	Mean 9.45% +/- 3.03% (79.8 +/- 33.2 mmol/mol) n=4	Mean 8.39% +/- 1.62% (68.2 +/- 17.6 mmol/mol) n=15	Mean 8.13% +/- 1.4% (65.4 +/- 15.3 mmol/mol) n=25	Mean 7.6% +/- 0.89% (59.6 +/- 9.7 mmol/mol) n=15
Cavanaugh **DNT score** **p=0.066**	Median 8.8% IQR 6.9-10.3% *Mean 8.7%* *(+/- 1.00)* *(71.6 +/- 11) mmol/mol* n=3	Median 8.1% IQR 7.3-8.7% *Mean 8.05%* *(+/- 0.45)* *(64.5 +/- 4.9 mmol/mol)* n=6	Median 7.5% IQR 7.1-9.1% *Mean 7.8%* *(+/- 0.63)* *(61.7 +/- 6.9 mmol/mol)* n=13	Median 7.1% IQR 6.5-8.0% *Mean 7.18%* *(+/- 0.38)* *(55 +/- 4.1 mmol/mol)* n=33

8.4.3 Numeracy and glycaemic control

Numeracy and glycaemic control appear to be linked, with the strength of this relationship varying from clear statistical significance to simple trend (Marden et al., 2012, Zaugg et al., 2014). Most

studies adjusted for confounding variables in their models, however some bias existed in the recruitment techniques (discussed below). Other potential confounders were not measured in all three studies, such as duration of diagnosis. Marden et al. found a statistical difference in mean HbA1c values for participants above and below level 2 numeracy (8.4 +/- 1.2% (68 +/- 13 mmol/mol) versus 9.2 +/- 1.7% (77 +/- 18 mmol/mol) p=0.004.)(Marden et al., 2012). This result is corroborated by Cavanaugh et al., who found a 10% decrease in DNT correlating to a 0.09% increase in HbA1c (95%CI 0.01-0.16% p=0.027) (Cavanaugh et al., 2008).

8.4.4 Numeracy according to diabetes type

This review specifically wished to examine the effect of numeracy on glycaemic control in people with T1DM. However, the inclusion of two studies using mixed populations has allowed identification of the difference between individuals with T1DM compared to T2DM. Cavanaugh et al. reported a negative association between numeracy and glycaemic control in those with T1DM. Although clinically relevant, it was not statistically significant due to inadequate sample size. Zaugg et al. reported an interaction effect between the type of diabetes and the DNT15 score; finding a negative correlation between numeracy level and glycaemic control in T1DM, after adjusting for gender and level of education (p=0.043) (Zaugg et al., 2014).

These findings suggest that sufficient numeracy is more important for those with T1DM. The studies author's remarked upon the greater level of numeracy required to achieve good glycaemic control in T1DM compared to T2DM, due to the numerical requirements (decimals, fractions, percentages and converting units of measure) associated with carbohydrate-counting and administering the correct dose of insulin (Marden et al., 2012, Zaugg et al., 2014). Higher numeracy levels were seen in those with T1DM compared to T2DM. However, no association between DNT score and insulin use was found within a mixed population (Cavanaugh et al., 2008).

8.4.5 Numeracy and self-care

Only one study examined the effect of numeracy on other measures of self-care. In Cavanaugh et al.'s mixed population higher numeracy was associated with higher levels of diabetes-specific knowledge (p=0.001) and greater self-efficacy (9% to 12.5% p=0.003).

8.4.6 Literacy and glycaemic control

The link between literacy and glycaemic control in T1DM is less convincing than that of numeracy. Only Marden et al. specifically examined this relationship, independent of numeracy, and found no

significant variation in mean HbA1c between the two groups above and below level 2 literacy (8.6 +/- 1.3% (70 +/- 15mmol/mol) compared to 8.8 +/- 1.6% (73 +/- 17mmol/mol) (p=0.56)). Moreover, Cavanaugh et al. report no association despite finding low literacy to be associated with lower DNT scores (p=0.001) and the afore mentioned effect of numeracy on glycaemic control.

8.4.7 The Impact of Socio-economic factors

Recognition of the complex interplay of demographics and socio-economic factors with glycaemic control resulted in all the studies considering such influences within their study design; either by controlling for covariates to reliably determine the true relationship between glycaemic control and health literacy and numeracy levels, or to explore how the factors themselves relate. While all of the studies considered age, gender and educational attainment, Cavanaugh et al. and Marden at al. also explored socio-economic status.

Numeracy appears to be independently associated with glycaemic control after controlling for socioeconomic factors. Linear regression modelling of glycaemic control with numeracy and health literacy when adjusted for age, gender, socio-economic deprivation (based on postcode), educational attainment and duration with diabetes showed that numeracy alone had a significant association (standardised coefficient β -0.17 (-1.18 to -0.07) p=0.027) (Marden et al., 2012). Despite Cavanaugh et al. using a mixed population, their regression analysis corroborates this, with modest association between HbA1c and DNT score, after adjusting for demographic and health factors.

Having found a correlation between numeracy and glycaemic control, Cavanaugh et al. explored characteristics associated with lower DNT scores. They found lower scores in individuals of older age, non-white ethnicity, lower educational attainment and lower socio-economic status (Cavanaugh et al., 2008). Although older age was associated with lower numeracy levels there appeared to be an inverse relationship with glycaemic control, both in a mixed population with HbA1c decreasing by 0.17% for every 5-year increase in age (CI, 0.10% to 0.24%; P=0.001) and in a T1DM only population (Marden et al., 2012, Cavanaugh et al., 2008).

Educational attainment appeared to influence glycaemic control, with those who left school at 18 achieving better glycaemic control than those that left at 16 (Marden et al., 2012). Zaugg et al. did not report a link between glycaemic control and education, but found a correlation between the highest level of education completed and the DNT-15 scores (p=0.004), after adjusting for gender, type of diabetes, and age (Zaugg et al., 2014).

8.4.8 Discussion

Despite only identifying three eligible studies, six themes were identified via narrative synthesis. Specifically, higher numeracy levels were associated with greater glycaemic control in adults with T1DM. This may reflect the nature of skills required to achieve success with carbohydrate counting and insulin dose adjustment associated with complete insulin deficiency seen in T1DM. The lesser degrees of insulin deficiency seen in T2DM may mean less precision is needed to achieve glycaemic control, accounting for the weaker effect of numeracy in this group of individuals.

Alternatively, the regularity with which people with T1DM use skills for dose adjustment may mean that numeracy improves overtime. This is supported by mixed population studies finding a higher proportion of people with T1DM in the top quartile of numeracy score (Cavanaugh et al., 2008, Trief et al., 2016). Along with the increased self-efficacy and diabetes knowledge found in those with greater numeracy. Cross-sectional study design means causality is uncertain, and can only be hypothesised at this stage.

In an era of increasingly collaborative patient-centred care the ability to navigate the healthcare system, understand instructions and compute health choices are important skills for self-management. It is surprising that insufficient evidence to support the effect of health literacy exists, possibly due to inadequate number of studies. Previous studies have found a relationship between health literacy and glycaemic control, with a trend seen in T1DM (Piatt et al., 2014).

Michie et al. hypothesise that behavioural change is due to the interaction between three components; capability, opportunity and motivation (COM-B model) (Michie et al., 2011). Numeracy appears relevant to 'opportunity' referring to 'factors that lie outside the individual that make the behaviour possible', including physical, mental and social aspects of the individual's thought process. I suggest poor numeracy has a detrimental effect on the ability to achieve target glycaemic control. To effectively improve self-care in individuals with low numeracy, the COM-B framework suggests interventions using education, persuasion and incentivisation (Michie et al., 2011).

The British 'Skills for Life' survey in 2003 found over half the nation had an average reading age of a 9-year-old (Kerr, 2007, The Public Accounts Committee, 2009). Similarly, 25% of American adults are functionally illiterate (The Council on Scientific Affairs, 1999). Improving individual numeracy has become of increasing importance to national governments, with the British government announcing plans to raise the functional literacy and numeracy of the working population to 95% by 2020. The economic argument for investing in up-skilling the nation is strong, with 13% increase in earnings for

1724 those who attend a basic mathematics course. Additionally, the government could reduce public
1725 health spending, as those with low health literacy have more hospital admissions (31.5% v 14.9%)
1726 (Baker et al., 1998).

1727 Healthcare professionals offer an alternative strategy. The American Medical Association
1728 recommend further education and funding for current and future healthcare professionals to gain
1729 skills to appropriately communicate with patients with limited literacy (The Council on Scientific
1730 Affairs, 1999). Language choice and communication are fundamental to deploy persuasive and
1731 incentivising techniques during the consultation. Through continuous professional development,
1732 skills can be learned to enable more comprehensive communication with patients with low literacy
1733 such as making their instructions more interactive and asking patients to do, write, say or show to
1734 prove understanding (Doak et al., 1996). Fewer than 5% of healthcare professionals currently check
1735 their patients' understanding of their medical consultation (Braddock et al., 1997). However, the
1736 healthcare professional's knowledge of their patients' numeracy or literacy ability alone appears to
1737 be insufficient to improve self-care in diabetes, and tailored education is necessary (Seligman et al.,
1738 2005). A recent randomised controlled trial used diabetes educational materials and methods
1739 tailored to an individual's needs versus standard educational methods. Both groups saw an
1740 improvement in HbA1c, which was significantly greater in the group receiving tailored education (-
1741 1.5% v -0.8%, p=0.005) at 3 months, but no longer significant at 6 months (-1.05% v -0.9%
1742 p=1)(Cavanaugh, 2009).

1743 A third strategy absolves the need for individual numerical skills via use of technology, for example
1744 insulin bolus calculators (either integrated with glucose meters or as smartphone applications),
1745 which automatically calculate appropriate insulin dose according to an algorithm and parameters
1746 defined by an individual's diabetes specialist (Schwartz and Guo, 2012, Zisser et al., 2010, Brancato
1747 et al., 2014, Barnard et al., 2012). These have been shown to improve adherence by overcoming
1748 some of the motivational components of good glycaemic control such as fears of hypoglycaemia, but
1749 have not yet been trialled specifically in people with reduced numeracy (Goebel-Fabbri et al., 2008).
1750 These technologies need to be user friendly, seamlessly communicating between glucometer and
1751 calculator with potential for digitalised carbohydrate portion estimation in the future. Poor
1752 numeracy appears to reduced use of more complicated insulin pump functions such as dual wave
1753 boluses (Patrakeeva et al., 2013). Further work is needed to ensure health inequalities are not
1754 widened by inadvertently restricting technology use to the health literate (Buysse et al., 2013).

Demographics such as educational attainment, employment status, age and ethnicity could be considered as other factors associated with 'opportunity' and therefore impact on glycaemic control. These factors may also be clues to poor numeracy, but are insufficiently correlated to absolve the need for assessment (The Council on Scientific Affairs, 1999). The lack of gold standard assessment for numeracy has limited our review, as different numeracy and literacy tests were used, making cross referencing and comparison of studies difficult. Additionally, comparison was made between two different health systems; where the USA insurance-based system has a greater number of adults with diabetes receiving diabetes education than the UK (57% in USA in 2010 versus 5.3% in UK in 2014-15) (Division of Diabetes Translation National Center for Chronic Disease Prevention and Health Promotion, 2014, Health and Social Care Information Centre et al., 2016). Despite this, we found a relationship between numeracy and HbA1c, making these results generalisable to other populations.

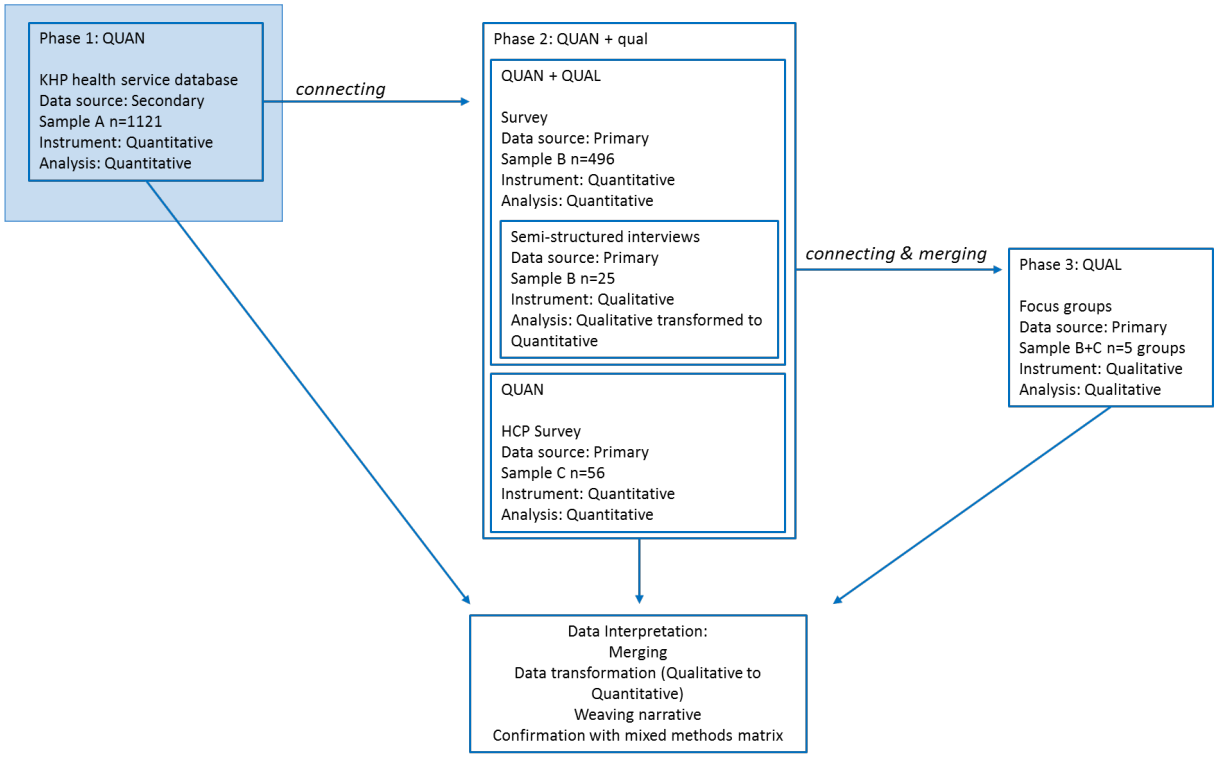
8.4.9 Conclusion:

Numeracy is associated with glycaemic control in people with T1DM, likely due to the degree of precision required in those with complete insulin deficiency. Further work is necessary to confirm this association, as well as define tools to appropriately identify those with lower numeracy. Interventions focusing on education, persuasion and incentivisation need to be developed to enable those with low numeracy to achieve glycaemic targets.

The following chapters will outline the data collected and analysed for the BUDiE study, later integrating the evidence from the systematic review with the primary data to draw substantial conclusions.

9 Phase 1: Database study

9.1 Methods

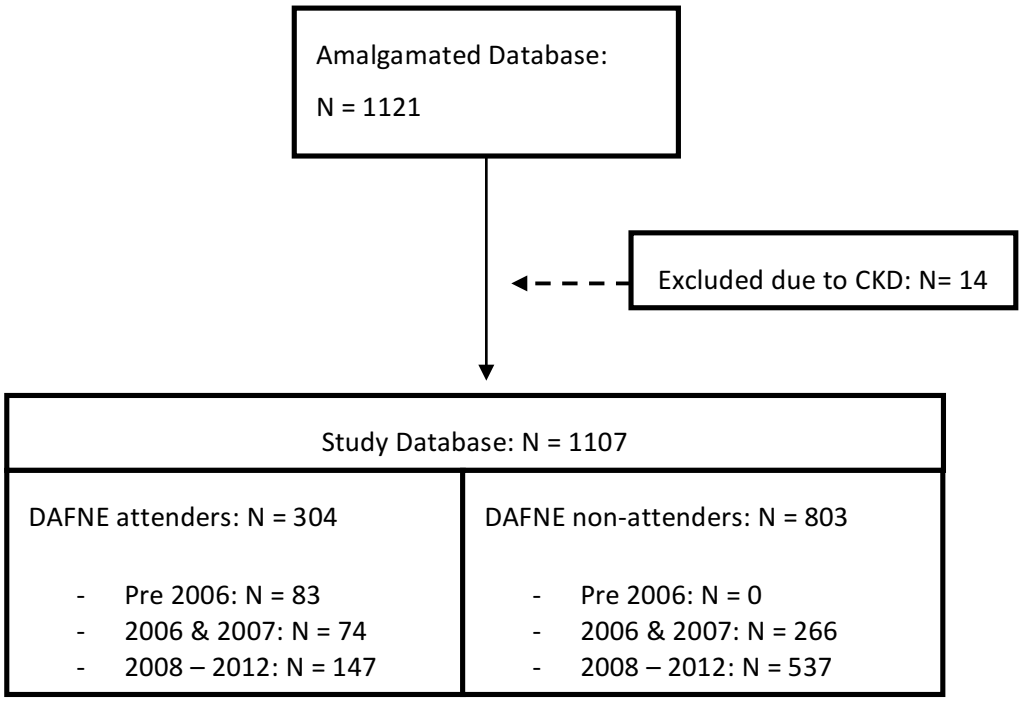


Phase 1 (P1) involved quantitative analysis of the local diabetes service use database from 2006-2012. This was analysed by attendance or not at DAFNE, according to local DAFNE graduate database. The methods for P1 have previously been described. There was no deviation from those set out in the methods chapter (7.2.2.1).

9.2 Results

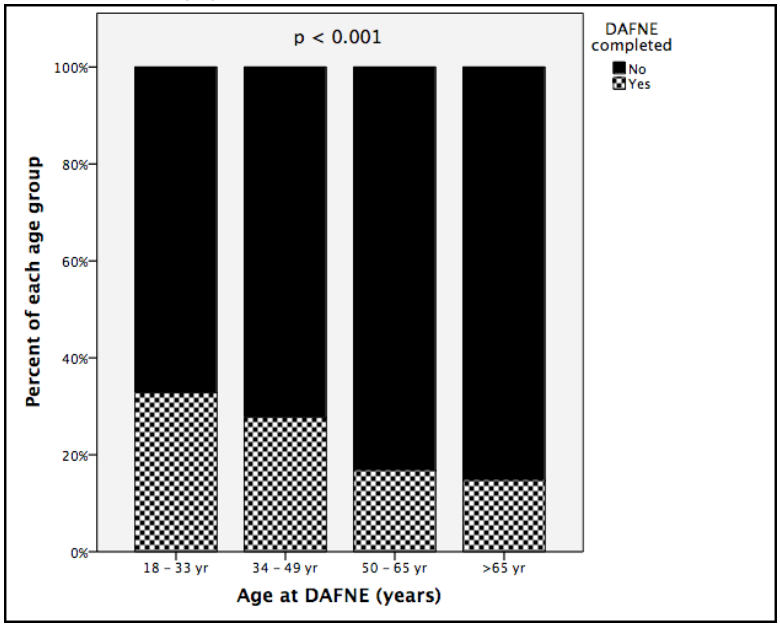
The database identified 1121 adults with T1DM in the two boroughs. Fourteen cases were excluded due to presence of advanced renal disease (CKD stage 5), leaving results from 1107 adults for analysis (Figure 9-1). The local DAFNE graduate database, for coinciding time-period, was used to divide the database according to attendance or not at DAFNE. Three hundred and four (27.5%) adults had attended and 803 adults had not attended DAFNE from 2006 to 2012. Eighty-three people had completed prior to the conception of the service use database, and therefore only their demographic characteristics could be analysed. All 803 non-attenders were allocated to a year of intervention (I), in order to create a control group from which to compare diabetes-related service use and diabetes outcomes. 3.6 non-attenders were allocated to every 1 DAFNE attender. The number varied each year and can be seen in Appendix J.

Figure 9-1: Number of people included and excluded in each analysis stage



Non-attenders were more likely to be men (48% vs 59%, p=0.002), BME group (30% vs 20%, p=0.001), four years older (39 vs 35 years old, p<0.001) and living in an area of social deprivation (IMD score 31 vs 28, p<0.001) (Table 9-1). There was a gradual decline in attendance rate according to categorised age groups (Figure 9-2).

Figure 9-2: Bar-chart of attenders and non-attenders according to total of each age group (in years). P value indicated (statistical significance taken as <0.05)



Diabetes-related service use in two years prior to year of intervention was analysed (I-2). Six hundred and eighty-four people had sufficient data for analysis (post-2008) with 3.2% (22) having

diabetes-related admissions within two years' prior of intervention. Five percent of the DAFNE cohort had been hospitalised, compared to 3% of the non-attenders in the same time frame. Although a trend was seen this did not achieve statistical significance.

Table 9-1: Baseline characteristics of DAFNE attenders and non-attenders.
Categorical data are presented as count with percentage. Other data are shown as median with interquartile range (IQR).
Statistical significance taken as p value of <0.05

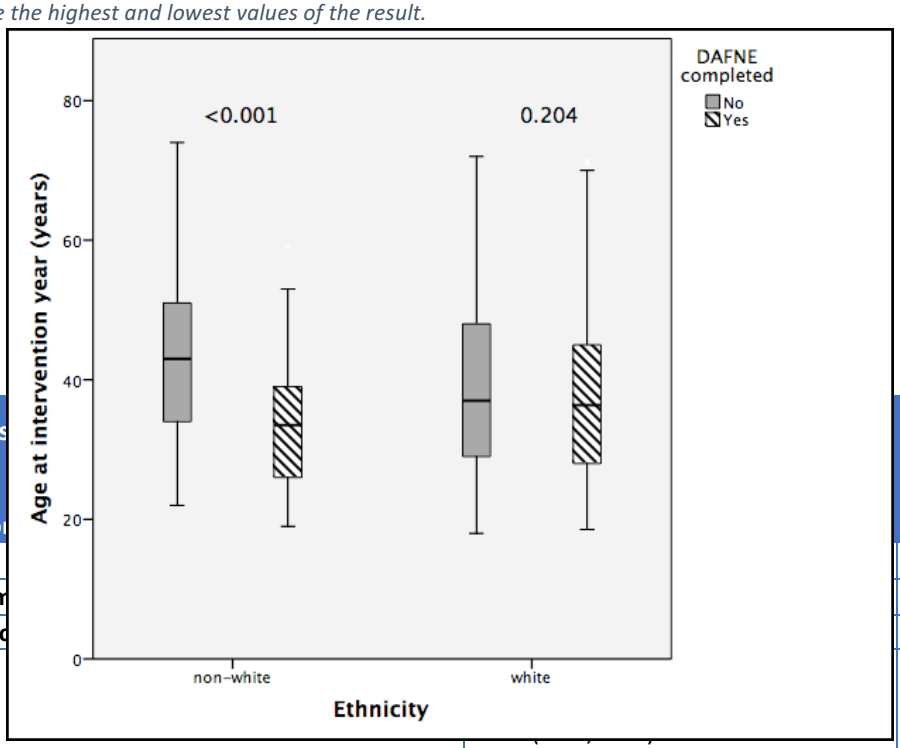
Variable		DAFNE (n=304)	Non-DAFNE (n=803)	p-value
Age at intervention (years)		35 (28-44)	39 (30-49)	<0.001
Gender	Male	147 (48%)	473 (59%)	0.002
	Female	157 (52%)	330 (41%)	
Duration of diabetes at intervention (years)		13 (6-22)	14 (8-23)	0.07
IMD score		28 (21-34)	31 (25-37)	<0.001
Ethnicity:	White (%)	244 (80%)	565 (70%)	0.001
	Non-white (%)	60 (20%)	238 (30%)	
HbA_{1c} at intervention (n 621) (%) **mmol/mol**		8.4% (7.6-9.6) 68 (60-81)	8.2% (7.3-9.4) 66 (56-79)	0.06
In-patient admission 2 years prior	Yes (22/684)	8/147 (5%)	14/537 (3%)	0.08
	No	139 (95%)	523 (97%)	

Subset analysis according to ethnicity; White or BME (187 African-Caribbean, 14 South-East Asian, 97 other), found that half as many men had attended (12% male vs 30% female, p<0.001) and a nine-year age difference existed between the attender and non-attender groups (34 vs 43 years old, p<0.001) in the BME group. Social deprivation was the only significantly different variable in the White group (IMD score 27 vs 30, p<0.001) (Table 9-2).

Table 9-2: Subset analysis of variables according to attendance or not at DAFNE by ethnic group.
Categorical data are presented as count with percentage. Other data are shown as median with inter-quartile range (IQR).
Statistical significance is taken as a p-value of <0.05.

Ethnicity	Variable		DAFNE	Non-DAFNE	p-value
BME (%)	Gender (n/total)	Male	20/165 (12%)	145/165 (88%)	<0.001
		Female	40/133 (30%)	93/133 (70%)	
	Age (years)		34 (26-39)	43 (34-51)	<0.001
	HbA1c (%) (mmol/mol)		9% (6.7-10.6) 75 (50-92)	8.7% (7.6-9.9) 72 (60-85)	0.26
	Index of Multiple Deprivation (IMD)		31 (22-38)	34 (28-38)	0.21
White (%)	Gender (n/total)	Male	127/455 (28%)	328/455 (72%)	0.12
		Female	117/354 (33%)	237/354 (67%)	
	Age (years)		36 (28-45)	37 (29-48)	0.20
	HbA1c (%) (mmol/mol)		8.3% (6.8-9.3) 67 (51-78)	8.1% (7.3-9.1) 65 (56-76)	0.51
	Index of Multiple Deprivation (IMD)		27 (21-32)	30 (24-36)	<0.001

Figure 9-3: Box and whisker plot according to DAFNE attendance, by age (in years) and ethnicity (white or non-white). The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the result.



Characteris (comparato		p value
Age (years)		0.001
Gender (fem		0.03
Ethnicity (nc		0.44
IMD score		<0.001
<25%[a]		
25-50%		0.007
50-75%	0.52 (0.35, 0.77)	0.001
>75%	0.53 (0.35, 0.80)	0.002
HbA1c at time of intervention		0.03
<7.5%[b]	ref	
7.5 – 9%	1.75 (1.13, 2.70)	0.01
>9%	1.96 (1.25, 3.08)	0.004
Diabetes-related admission 2 years prior to intervention	2.22 (0.88, 5.63)	0.09
Duration of diabetes at time of intervention (years)	1.00 (0.98, 1.01)	0.50

A binary logistic regression model using non-attendance at DAFNE as the norm assessed the factors influencing uptake of DAFNE (

Table 9-3). Variables that were statistically significant in univariate analysis, or were likely to be confounders based on previous research, were included in the exploratory model. Three variables were incomplete: IMD score, HbA1c and service use. These missing data were categorised, as per methodology (7.4.2.1), to allow inclusion in the model; IMD score into quartiles, HbA1c defined according to the upper and lower target levels of QOF (<7.5%, 7.5-9% and >9%) and service use into a binary variable (admission or not) (NHS England, 2014). After categorisation 152 cases still had more than one variable missing and were therefore excluded from analysis. The model predicted 73% of attendances with Hosmer and Lemeshow goodness of fit test showing calibration with the model (Chi^2 11.2 p=0.19) and Nagelkerke R^2 0.12.

Binary logistic regression analysis found four key variables were associated with attendance at DAFNE (

Table 9-3):

- Deprivation was the most influential variable; with those from areas of social deprivation being half as likely to attend (IMD >75th centile, OR 0.48, 95% CI 0.32-0.73 p=0.001).
- Age effected attendance by reducing likelihood by 23% for every additional decade of life (OR 0.98, 95% CI 0.96-0.99, p=0.001).

Characteristics (comparator)	Attendance at DAFNE (n = 1107) OR (95% CI)	p value
Age (years)	0.98 (0.96, 0.99)	0.001
Gender (female)	0.74 (0.56, 0.98)	0.03
Ethnicity (non-white)	0.86 (0.60, 1.25)	0.44
IMD score		<0.001
<25%[a]	ref	
25-50%	0.58 (0.39, 0.87)	0.007
50-75%	0.52 (0.35, 0.77)	0.001
>75%	0.53 (0.35, 0.80)	0.002
HbA1c at time of intervention		0.03
<7.5%[b]	ref	
7.5 – 9%	1.75 (1.13, 2.70)	0.01
>9%	1.96 (1.25, 3.08)	0.004
Diabetes-related admission 2 years prior to intervention	2.22 (0.88, 5.63)	0.09
Duration of diabetes at time of intervention (years)	1.00 (0.98, 1.01)	0.50

- Male gender made attendance less likely (OR 0.74, 95% CI 0.56-0.98, p=0.032).
- The influence of glycaemic control was positively correlated; as likelihood of attendance at DAFNE increased as HbA1c increased from <7.5%; mean HbA1c >9% doubled the chance of attendance (OR 1.96, 95%CI 1.25-3.08, p=0.004).

Duration of diabetes had no influence on attendance. Similarly, previous diabetes-related admission did not reach significance despite a high odds ratio (OR 2.22 p=0.09). Ethnicity, which reached statistical significance in univariate analysis, was not an influencing factor in multivariate analysis, after adjusting for other variables including deprivation

Table 9-3: Binary logistic regression model for attendance at DAFNE.
[a] lowest quartile (<25% group) used as reference group for IMD data. [b] HbA1c < 7.5% used as reference group for HbA1c data. Odds Ratio (OR) and 95% Confidence Interval (95% CI) shown for each variable.

There were varying amounts of missing data; HbA1c 364 (33%) missing cases, IMD score 108 (10%) missing cases, and hospital admission 423 (38%) missing cases. Sensitivity analysis involved univariate analysis of three key variables (age, ethnicity and gender) between the cases with present and absent data for each variable with missing data (Appendix K). There was a significant difference in age across all the missing variables and ethnicity was different in cases missing IMD and hospital admission data. Therefore, additional sensitivity analysis using Forward Wald regression was run after exclusion of 112 cases with more than one missing variable. Nine hundred and fifty-five (86%) remaining cases were included in multivariate analysis. The same influential factors were identified, with each factor having a similar influence on attendance as the initial model, suggesting that the categorisation of missing cases (to allow inclusion in the original model) had no detrimental effect on the multivariate analysis results (Appendix L).

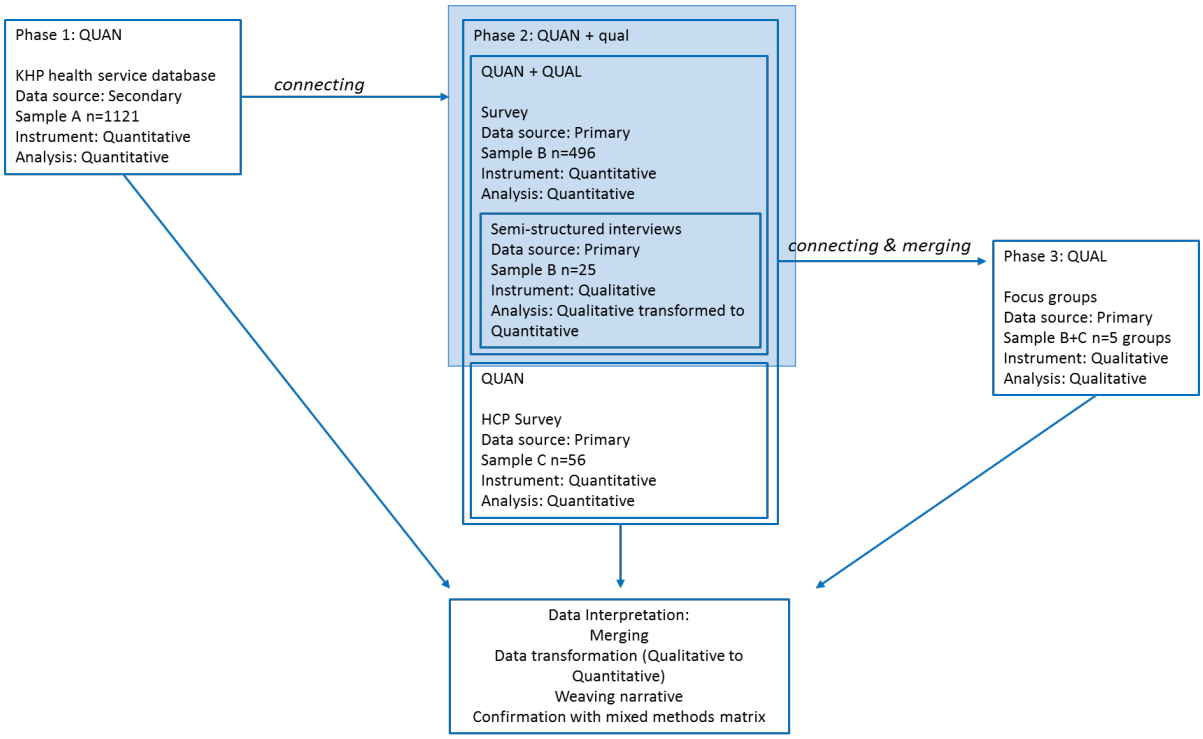
Characteristics (comparator)	Attendance at DAFNE (n = 1107) OR (95% CI)	p value
Age (years)	0.98 (0.96, 0.99)	0.001
Gender (female)	0.74 (0.56, 0.98)	0.03
Ethnicity (non-white)	0.86 (0.60, 1.25)	0.44
IMD score		<0.001
<25%[a]	ref	
25-50%	0.58 (0.39, 0.87)	0.007
50-75%	0.52 (0.35, 0.77)	0.001
>75%	0.53 (0.35, 0.80)	0.002
HbA1c at time of intervention		0.03
<7.5%[b]	ref	
7.5 – 9%	1.75 (1.13, 2.70)	0.01
>9%	1.96 (1.25, 3.08)	0.004
Diabetes-related admission 2 years prior to intervention	2.22 (0.88, 5.63)	0.09
Duration of diabetes at time of intervention (years)	1.00 (0.98, 1.01)	0.50

9.3 Key Points & Discussion

1. 27.5% of adults with T1DM using local diabetes services had attended DAFNE between 2006 to 2012
2. Non-attenders were significantly more likely to be older, male, from BME groups and living in social deprivation (per IMD score).
3. Sub-set analysis found a difference in significant variables according to ethnicity: White non-attenders were living in areas of social deprivation, whilst BME group non-attenders were older and male.
4. Four key variables influenced attendance after adjustment for measured confounders in multivariate analysis: Age, gender, IMD score and HbA1c.
5. Deprivation (per IMD) appeared to explain the influence of ethnicity on attendance, as IMD was no longer significantly different in subset analysis and ethnicity was not associated with attendance after adjustment for IMD in multivariate modelling.

10 Phase 2 Sample B

Phase 2 (P2) makes up the bulk of my project, constituting two different samples (B and C) and using both qualitative and quantitative methods. Below I outline the recruitment strategy and the methodology, with results and key points taken from P2 into P3.



10.1 Methods

P2 methods have been outlined in the Methodology chapter (7.4.2.2). The process of recruitment was iterative and required changes to increase response rate, as outlined below.

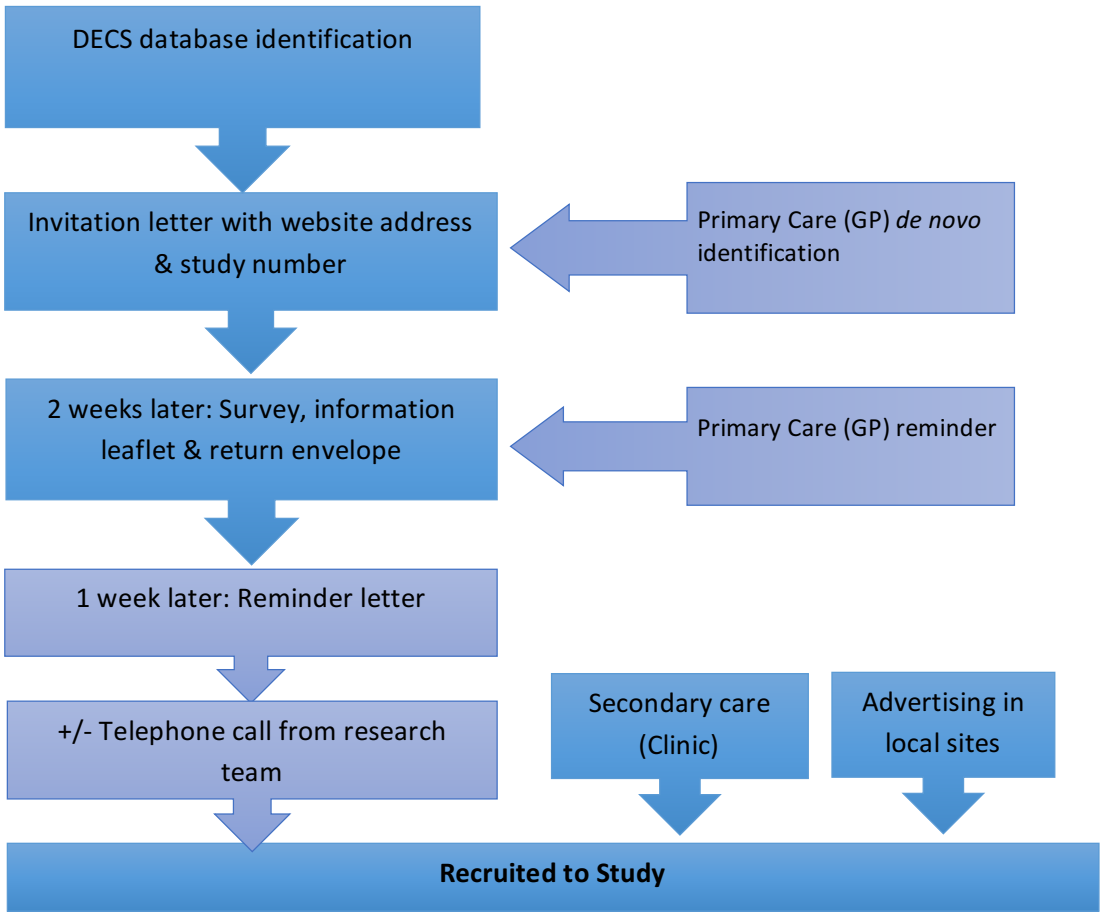
10.1.1 The recruitment process

The power calculation showed that 306 adults needed to be recruited but I was keen to achieve a higher response rate, to ensure that sufficient quantities of the harder to reach communities were recruited (ncalculator-margin.of.error). Previous research reports response rates from postal surveys ranging from 33 to 71% , with one method achieving response rates of 50-80% based on a total of five mailings, two of which included surveys and the use of registered mail (Dillman, 1991, Sheldon et al., 2007b). Experience in our secondary care setting suggested that a 75% response rate could be achieved with direct face-to-face recruitment (Ozcan et al., 2013). However, this was within a tertiary referral clinic which receives referrals from across the UK, and a greater proportion of CSII users (around 33%), who usually represent 12% of the T1DM population and require a level of

interaction with self-care to qualify for CSII therapy (Health and Social Care Information Centre et al., April 2016, Ozcan et al., 2013).

One thousand, six hundred and twenty-two adults with self-reported T1DM were identified via the DECS database, 48 were excluded because they had previously opted out of research, were medically unfit or did not have a registered address (see Figure 10-2 for CONSORT flow diagram). Recruitment was iterative in order to achieve maximal completion and recruitment rates. In February 2015, the first wave of letters was sent out by the DECS team to 500 people as per the recruitment pathway, shown in darker blue in Figure 7-4. This first wave of recruitment yielded a response rate of 20%; about 60% of respondents had attended DAFNE. Response in clinic had been more fruitful with few people declining to participate. It was therefore decided that poor response was primarily due to inertia or other priorities preventing more people from completing the survey, and that a direct approach could overcome this.

Figure 10-1: Recruitment pathway illustrating identification of participants and methods used to recruit them. Light blue boxes depict steps added after first wave recruitment following REC accepting substantial amendment.

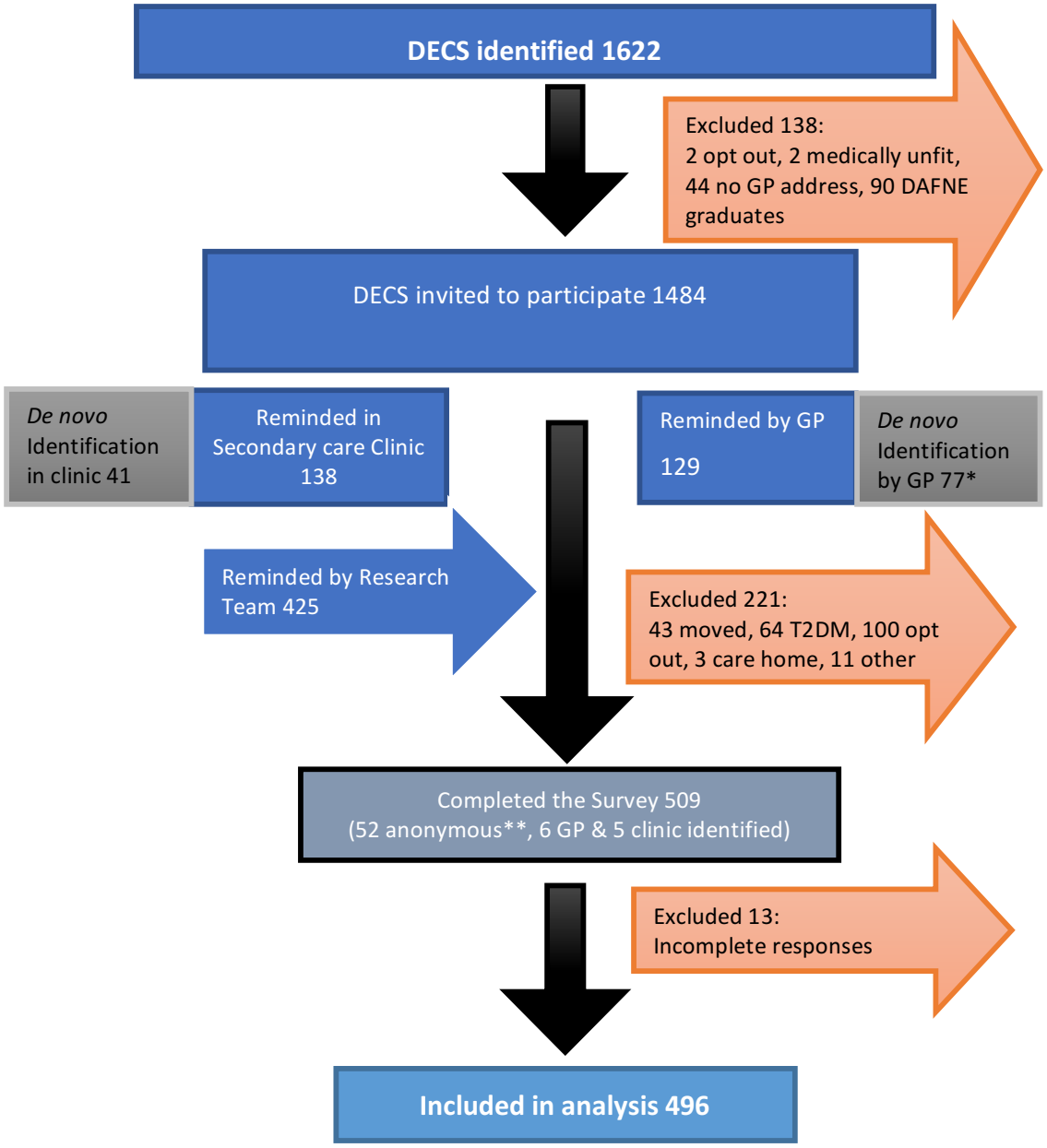


I submitted a substantial amendment to the Research and Ethics Committee (REC) in March 2015, which permitted me direct access to individual's contact information held on DECS database, so I could identify and track respondents, as well as telephone potential participants to check that they had received the survey and help them overcome any barriers to completing it, such as literacy or visual difficulties.

In order to focus resources on recruiting lesser-heard individuals, the second wave of postal invitations excluded those known to have completed DAFNE. I combined the local DAFNE register from both GSTT and KCH with the DECS database to identify and exclude 90 DAFNE graduates. Telephone calls were targeted at traditionally hard to recruit groups (particularly young, male, BME groups), as indicated by their demographic details held on DECS database (Sheldon et al., 2007b).

In addition to these changes to the recruitment pathway, the Primary Care Research Network (PCRN) invited and remunerated GP surgeries (identified via DECS to have more than fifteen eligible participants) to help with recruitment. From July 2015 eleven surgeries in Southwark and Lambeth participated by searching their database for all eligible registered adults. Those who had already been identified via DECS and received, but not responded to an earlier invitation (129 people), were sent a reminder letter on surgery letterhead, whilst newly identified participants (77 people) were sent an invitation letter and survey Figure 10-2). Recruiting from primary care provided another contact point, particularly for those not attending specialist care. It also acted upon comments from the the study advisory group that the use of DECS letterheads may have caused some confusion and/or been less incentivising than a more obvious indication that the research was being done by HPCs involved in delivering diabetes services.

*Figure 10-2: CONSORT diagram of the recruitment process and numbers, with those included and excluded at each level. *132 identified but assumed 42% ineligible with T2DM therefore 77 newly identified eligible potential participants invited. **Prior to substantial amendment accepted by REC the study team were not able to identify people who completed surveys without entering their study numbers, additionally some people chose to remain anonymous in either paper or online survey. Turquoise denotes those identified by DECS database; grey denotes newly identified; red indicates excluded & blue indicates total participants from every source.*



Recruitment involved multiple contact points; from research, diabetes and primary care teams. My assumption that the DECS database compromised a complete list of all eligible participants in the two boroughs was false, with additional eligible participants being identified in healthcare settings. This meant, coupled with the ability to complete the online survey anonymously, that until I was given access to the DECS database I was unable to track individuals. I could not clearly identify the exact number of individuals invited to participate, so response rates were estimated based on

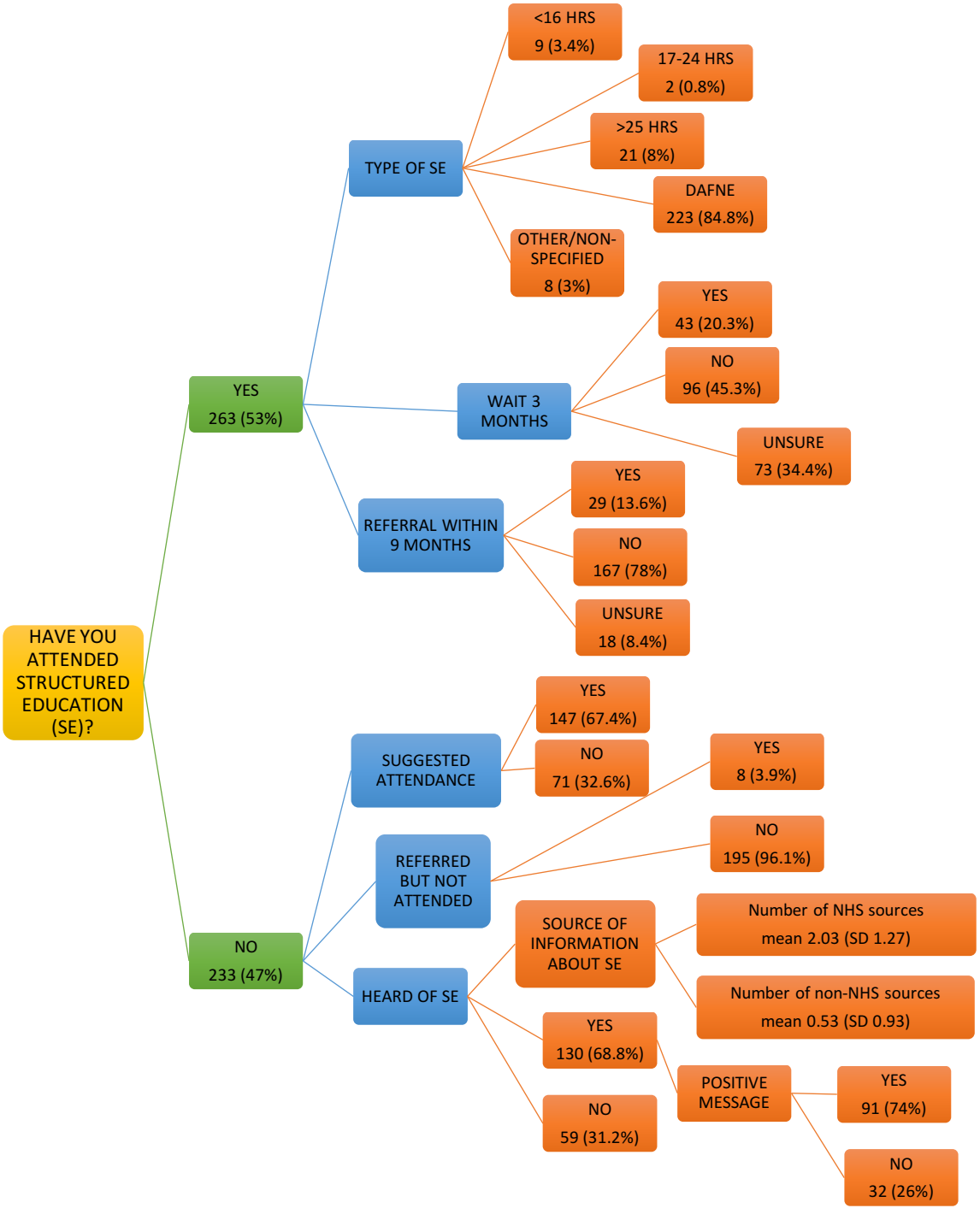
number invited via DECS and from healthcare settings. Working with the PCRN was of value although time consuming, as I needed to visit each GP surgery and provide support to send study letters. Where I could access the primary care records I could confirm diagnostic codes. In these four surgeries, 20 of the 48 indentified as potentially eligible had T2DM, equating to 42%. To calculate response rate, I have assumed that this was the case throughout primary care.

Overall, 1610 adults with T1DM were invited to participate in the BUDiE study. 1484 were identified via the DECS database and an additional 41 and 77 were identified in secondary and primary care respectively. A total of 509 surveys were returned, 110 people told me of their ineligibility and 97 contacted me to opt out of the study. The response rate was therefore 34.1% (509/1492). Of the 509, 496 had more than half of the first two sections completed. The CONSORT diagram of recruitment process is shown in Figure 10-2.

11 Phase 2 Sample B: Survey Results

Over 500 surveys returned. After removal of duplicates and incomplete (less than 50%) responses, 496 survey responses were included in analysis.

Figure 11-1: Flowchart of responses to the survey.
496 cases included but in some instances responses missing so count (n) included to allow appreciation of the number of responses.



From the 496 survey results analysed. 53% of respondents had completed some form of SE. The majority had completed DAFNE or another course with more than 25 hours learning. Half of those attending SE did not have to wait more than 3 months for a place. Most people were not referred to SE within 9 months of being diagnosed. This is likely because SE was not available at the time of their diagnosis, or that up until 2015 the NICE guidelines did not recommend a specific time for referral. This was due to evidence suggesting that people would gain less if they were referred during their honeymoon period, as they would not need to be as accurate with insulin dose adjustment therefore reaping less benefit from experiential learning.

47% of respondents had not completed SE. Of these 2/3 had either heard of SE and or been suggested to attend. Of those who had heard of SE, ¾ reported that their HCP was positive about the course. Respondents had 2.5 different sources of information about SE, a quarter of which was non-NHS source, such as a diabetes charity or websites. A small number of respondents had accepted a referral to DAFNE and not attended. Most of these people gave reasons for not being able to attend from acute illness requiring emergency treatment, to family bereavements.

Variable	Respondents	Non-respondents	p value
Age (years)	41 (32-51)	39 (30-52)	0.25
Gender (male)	57%	58%	0.74
Ethnicity (white)	82%	58%	<0.001
Employment status			0.13
Employed	64%	67.2%[a]	
Unemployed	8.6%	10.5%	
Educational attainment			<0.001[b]
University level	68%	45%[a]	
Primary school or less	3%	13%	
Born in UK	75%	63.5%[a]	0.002[b]

Figure 11-2: Table of study respondents identified via DECS, compared to non-respondents or population data from local borough census data (based on working population of 211,400[a]) (Southwark Council, May 2014, Southwark Council, 2012). Median and inter-quartile range for continuous data. Categorical data reported as count and percentage. Statistical significance taken as p < 0.05. [b] Online calculator used to test statistical significance where raw data not available to research team(MedCalc)(MedCalc)(MedCalc)(MedCalc)(MedCalc).

The respondent's characteristics were compared to that of the non-respondents taken from the DECS database, or local census details. The respondents were of similar age and had a similar gender split compared to non-respondents. A smaller proportion of respondents were from BME groups. Respondents had higher educational attainment but no difference in employment status compared to the local population.

11.1 Socio-demographic characteristics of respondents.

Table 11-1: Table describing socio-demographic characteristics of the study population divided by attenders and non-attenders of SE.
Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only. Categorical data reported as count and percentage. Statistical significance taken as $p < 0.05$.

Variable	Study group	Non-Attenders	Attenders	p value
Age (years) n 443	38 (30-50)	36 (29-51)	38 (30-50)	0.37
Gender (Male) n 479	278 (58%)	152/227 (67%)	126/252 (50%)	<0.001
Ethnicity				0.008
White	395 (82%)	175 (78%)	220 (87%)	
Black	56 (12%)	35 (15%)	21 (8%)	
Asian	13 (3%)	10 (4%)	3 (1%)	
Other	16 (3%)	8 (4%)	8 (3%)	
Born in UK (Yes) n 478	356 (75%)	156/228 (68.4%)	200/250 (80%)	0.003
Employment status				0.002
Employed	312 (64%)	137 (60%)	175 (68%)	
Self-Employed	65 (13.3%)	22 (10 %)	43 (17%)	
Unemployed	42 (8.6%)	28 (12%)	14 (5%)	
Studying	26 (5%)	16 (7%)	10 (4%)	
Caring	11 (2%)	8 (3%)	3 (1%)	
Retired	31 (6%)	18 (8%)	13 (5%)	
Marital status				0.231
Married	235 (49.7%)	104 (46%)	131 (52.6%)	
Divorced	23 (5%)	15 (7%)	8 (3%)	
Widowed	5 (1%)	3 (1%)	2 (1%)	
Single	210 (44%)	102 (46%)	108 (43%)	
Dependants (No) n 476	362 (76%)	172/227 (76%)	190/249 (76%)	0.891

The demographic results for those attending SE (attenders) compared to non-attenders showed a difference in gender, with fewer males attending SE. In contrast to the P1 results, there was no difference in age. People from BME groups were less likely to attend, as well as those born outside of the UK. Levels of unemployment were higher in the non-attender groups, with a higher proportion of self-employed people seen within the attender group. There was no difference between the groups for presence or absence of dependants.

11.2 Educational characteristics of respondents and other associated factors.

Table 11-2: Table illustrating the education and information finding characteristics of the study group and between those attending and not attending SE.
Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only. Categorical data reported as count and percentage. Statistical significance taken as $p < 0.05$. [a]Confidence filling form as measure of health literacy (HL) scored from 1-5 (1 being not at all confident). [b]Subjective Numeracy Score (SNS) scored from 1-6. [c]Healthcare professional (HCP) message about structured education (SE) scored from 1-5 (5 being extremely positive).

Variable	Study group	Non-Attenders	Attenders	p value
Educational attainment				<0.001
Primary or less	14 (3%)	13 (6%)	1 (0.5%)	
Secondary school	141 (29%)	86 (38%)	55 (21%)	
University or above	331 (68%)	129 (56%)	202 (78%)	
English language				0.059
1st Language	425 (87%)	191 (83%)	234 (90%)	
2nd language fluent	48 (10%)	29 (13%)	19 (7%)	
Conversational or less	17 (4%)	11 (5%)	6 (2 %)	
Confidence filling form[a]	4.57 +/-0.8	4.34 +/-1.05	4.69 +/-0.65	0.001
(n 487)	5 (4-5)	5 (4-5)	5 (5)	
Marginal HL	44 (9%)	26/230 (11%)	18/258 (7%)	0.066
SNS[b]	4.64 (+/- 1.1)	4.46 +/- 1.19	4.79 +/- 1.0	0.001
(n 486)	4.88 (3-5.38)	4.75 (3.88-5.38)	5 (4.38-5.5)	
Ability	5.25 (4.25-6)	5 (4-6)	5.25 (4.5-6)	0.01
Preference	4.5 (3.75-5.25)	4.5 (3.5-5)	4.75 (4-5.5)	0.01
HCP message about SE[c]	5 (3-5)	4 (4-5)	5 (4-5)	<0.001
(n 423)				
Less than positive	72 (17%)	43 (24%)	29 (12%)	0.001
Source of diabetes advice (n 490)				
Total number	2.59 +/- 1.5	2.41 +/- 1.4	2.76 +/- 1.5	0.005
		2 (1-3)	2 (2-4)	
Percentage non-NHS	20% (+/- 26)	19% +/- 27	20% +/- 25	0.341
		0 (0-33)	0 (0-33)	

Educational attainment affected attendance at SE, with a much higher attendance amongst university educated respondents. How people accessed information about their diabetes varied across the group. Attenders had more sources of diabetes advice, but a similar proportion of these were non-NHS sources. Other factors associated with education such as health literacy, as measured using a screening question about confidence in filling in medical forms, and subjective numeracy, also impacted on attendance, with lower levels amongst those with low health literacy or numeracy. Categorising health literacy into marginal/inadequate or adequate levels, according to the validation article, found no significant difference.

Figure 11-3: Box and whisker plot of health literacy screening question by attendance or not at SE. The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the results with outliers illustrated individually with star or circle.

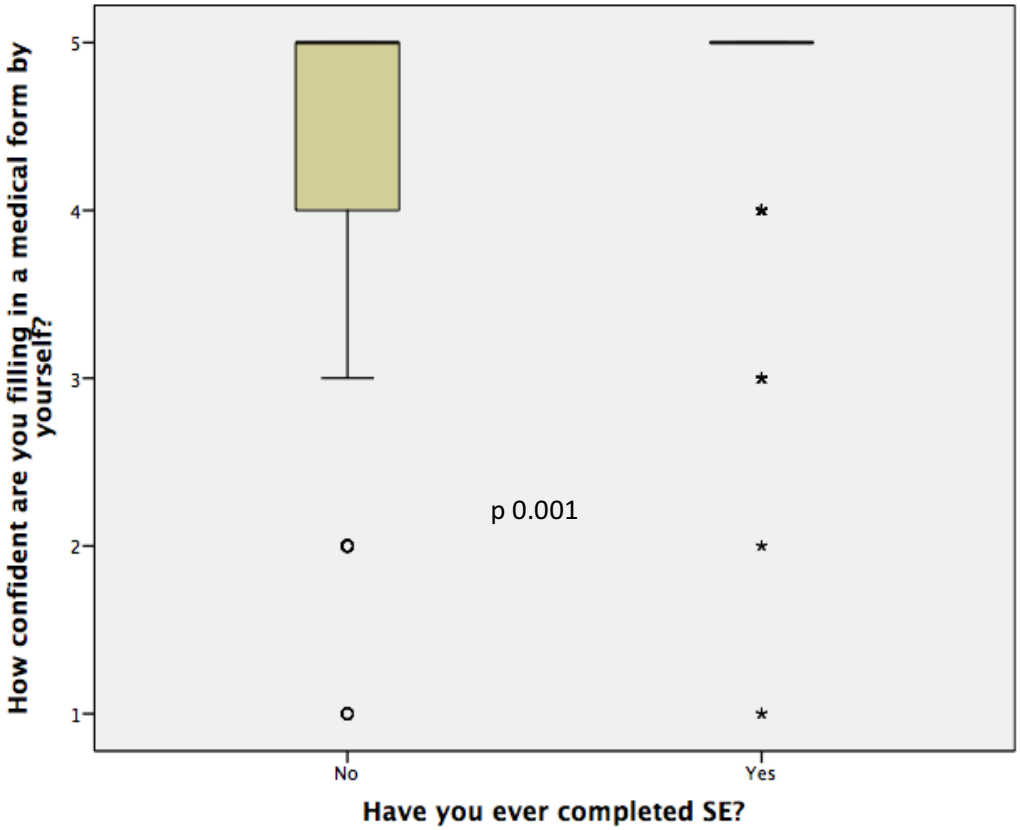


Figure 11-3 illustrates the health literacy within the attenders and non-attenders group. It shows a much wider spread in ability within the non-attender group compared to the attender group that were all very confident in completing medical forms by themselves. The strength of message received by people about SE from their HCP was significantly different between the groups, with attenders reporting a higher score (1-5). 17% of respondents reported receiving a less than positive (<3) message from their HCP about SE, and as a categorised variable this remained significantly different between the groups.

Figure 11-4: Chart illustrating the relationship between positive message (1 = not positive to 5 = extremely positive) from healthcare professional about SE and corresponding attendance at SE.

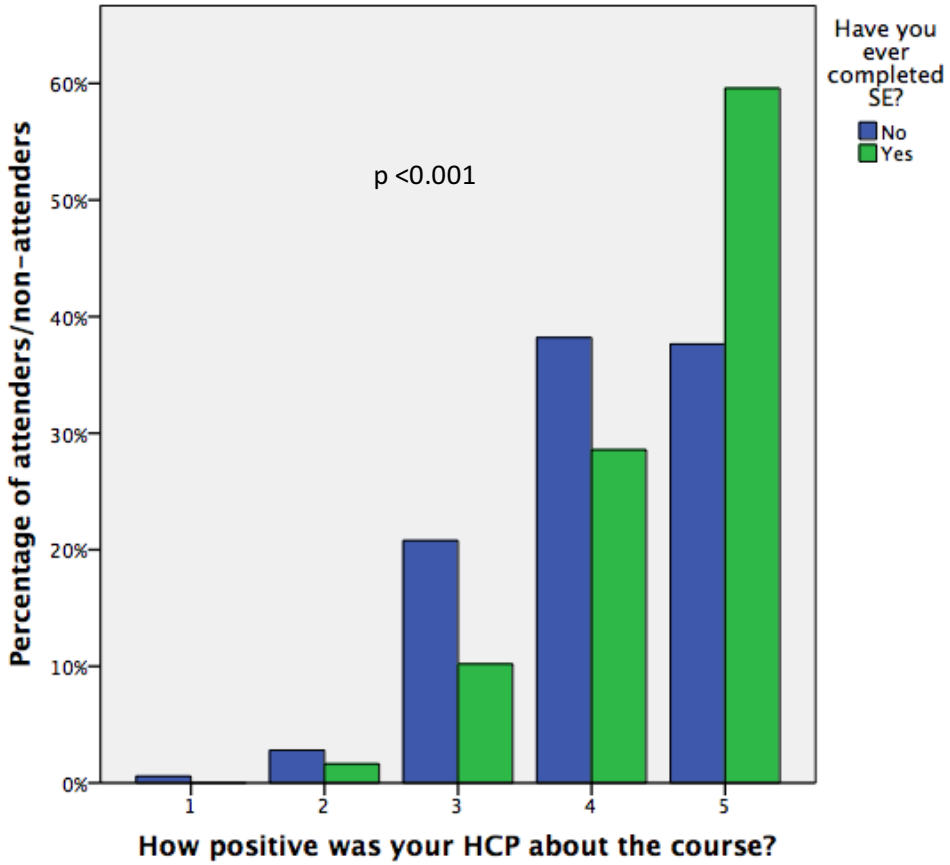


Figure 11-4 illustrates the spread of scores given to strength of message received about SE from HCPs by attendance or not at SE. The non-attenders reported less positive message, although some people who attended SE did report a neutral or less than positive message yet still attended.

11.3 Validated well-being and self-efficacy scores.

There was no difference in any of the validated well-being scores used in the survey between the groups. They reported the same level of confidence in their diabetes self-care abilities, the same quality of life the same impact of their health on social roles and activities, as well as the same scores for depression screening questions and levels of diabetes related distress.

Table 11-3: Table of validated scores related to psychology, quality of life and function. Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only. Categorical data reported as count and percentage. Statistical significance taken as p < 0.05. [1]CIDS (Confidence in Diabetes Self-care Scale) score 1 to 5 (5 being completely confident), transformed to a 0-100 scale using medical outcome survey scoring technique. [2]Depression is composite score of those screening positive in PHQ2 (>2) or those receiving treatment (either medication or psychological therapy). [3]PHQ-2 (Patient health Questionnaire-2) score from 0 to 6 (>2 indicating a high risk of depression). [4]Problem areas in diabetes score – 5 item (PAID5) score from 0 to 20 (0 being least distressed). [5]Stanford social/role activities limitation score (SSRALS) scored from 0 to 4 (0 being no limitation), transformed to mean of the 4 questions. [6]Quality of life (QOL) score from 0-10 (10 being best quality of life).

Variable	Study group	Non-Attenders	Attenders	p value
CIDS[1]	67 (57-74)	66.5 (56-74)	67 (59-74)	3.03
n 424				
Depression[2] (Yes)	182 (37%)	91/217 (42%)	91/251 (36%)	0.209
n 468				
PHQ-2[3]	0.95 +/- 1.23	1.05 +/-1.339	0.87 +/- 1.25	
n 407	0 (0-2)	0 (0-2)	0 (0-2)	0.155
PAID[4]	6.5 +/- 5.9	6.54 +/-6.37	6.46 +/- 5.5	
n 415	5 (2.5-10)	5 (1.25-10)	5 (2.5-10)	0.516
SSRALS[5]	0.64 +/- 0.85	0.63 +/- 0.82	0.66 +/- 0.88	
n 406	0.25 (0-1)	0.25 (0-1)	0.25 (0-1)	0.914
QOL[6]	7.1 +/- 1.9	6.99 +/- 2	7.17 +/- 1.8	
n 406	8 (6-8)	8 (6-8)	7 (6-8)	0.62

11.5 Diabetes-related care and service use

Table 11-4: Table of diabetes related service use.
Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only.
Categorical data reported as count and percentage. Statistical significance taken as $p < 0.05$.

Variable	Study group	Non-Attenders	Attenders	p value
Diabetes duration (years) n 483	17 (10-26)	17 (9-27)	18.5 (12-26)	0.32
Insulin Regimen				<0.001
MDI – OD	146(31.6%)	103(47.5%)	43 (17.6%)	
MDI -BD	197 (42.6%)	67 (30.9%)	130(53.1%)	
CSII	71 (15%)	10 (4.6%)	61 (24.9%)	
Other	48 (10.4%)	37 (17.3%)	11 (4.5%)	
Total service use n 394	7.5 (9)	7 (8)	8 (9)	0.742
Total visits	5 (3-9)	5 (3-9)	5 (3-9)	0.818
Additional contacts	1 (0-4)	1 (0-4)	2 (0-4)	0.21
Attending Secondary care n 405	345 (85.2%)	151 (80.7%)	194 (89%)	0.014
	3.47 +/-3.8	3.65 +/-4.5	3.32 +/-3.1	
Number of visits	2 (1-4)	2 (1-5)	3 (2-4)	0.136
Additional contacts	0 (0-2)	0 (0-2)	0 (0-2)	0.095
Number visits/contacts with community care	0.4 +/- 1.4	0.52 +/- 1.6	0.29 +/-1.1	0.04
	0 (0)	0 (0)	0 (0)	
Admissions (number of days)	0.15 +/- 0.8	0.22 +/- 1.1	0.09 +/-0.38	0.033
	0 (0)	0 (0)	0 (0)	
Sick days	4.49 +/- 22	6.5 +/- 29.4	3.09 +/- 12.1	0.287
	0 (0-2)	0 (0-2)	0 (0-1)	

There was a significant difference in insulin regimen between the groups; with more attenders on MDI-BD or CSII. There was a significantly higher proportion of non-attenders attending community care (p=0.04). Sixteen respondents (4%) had not seen a healthcare professional in the past 12 months, half of whom had attended SE. Five of these had neither visited nor spoken with a healthcare professional in the past 12 months.

There was no difference in overall service use across the groups (p=0.742), including both face to face clinic appointments, as well as contacts such as skype consultations, email or telephone contact. There was a difference in proportions of people attending secondary care (80.7 vs 89% p=0.014). For those attending secondary care, there was no difference in the number of visits or contacts per year (p=0.136 and p=0.095). People who had attended SE had the same number of days off sick as non-attenders but fewer hospital admissions (p=0.287 and p=0.033). Categorising the data into its presence or absence helped overcome possible skewing caused by outliers with multiple visits or admissions. Analysis as categorical variables produced the same result (admissions p 0.035, sick days' p 0.38). Within the hospital admission group there were outliers; two respondents

reported more than three hospital admissions. With these two respondents removed the result remained significantly different with mean admissions 0.13 +/- 0.337 (median 0 (0)) for non-attenders and 0.07 +/- 0.256 (median 0 (0)) for attenders (p 0.03). 93.4% of respondents reported ten or fewer sick days. Six respondents reported at least 100 sick days in the past 12 months, with these removed the mean number of sick days was 2.56 +/- 9.14 (median 0 (2)) for non-attenders and 2.29 +/- 8.28 (median 0 (1)) for attenders (p=0.45).

11.7 Diabetes control and complications – acute and chronic

Table 11-5: Table of diabetes control and complications.
Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only. Categorical data reported as count and percentage. Statistical significance taken as p < 0.05. [a] Hypoglycaemia awareness defined according to Gold score. IHA = impaired hypoglycaemic awareness. [b] No adjustment made for respondents who skipped question because no knowledge of HbA1c.

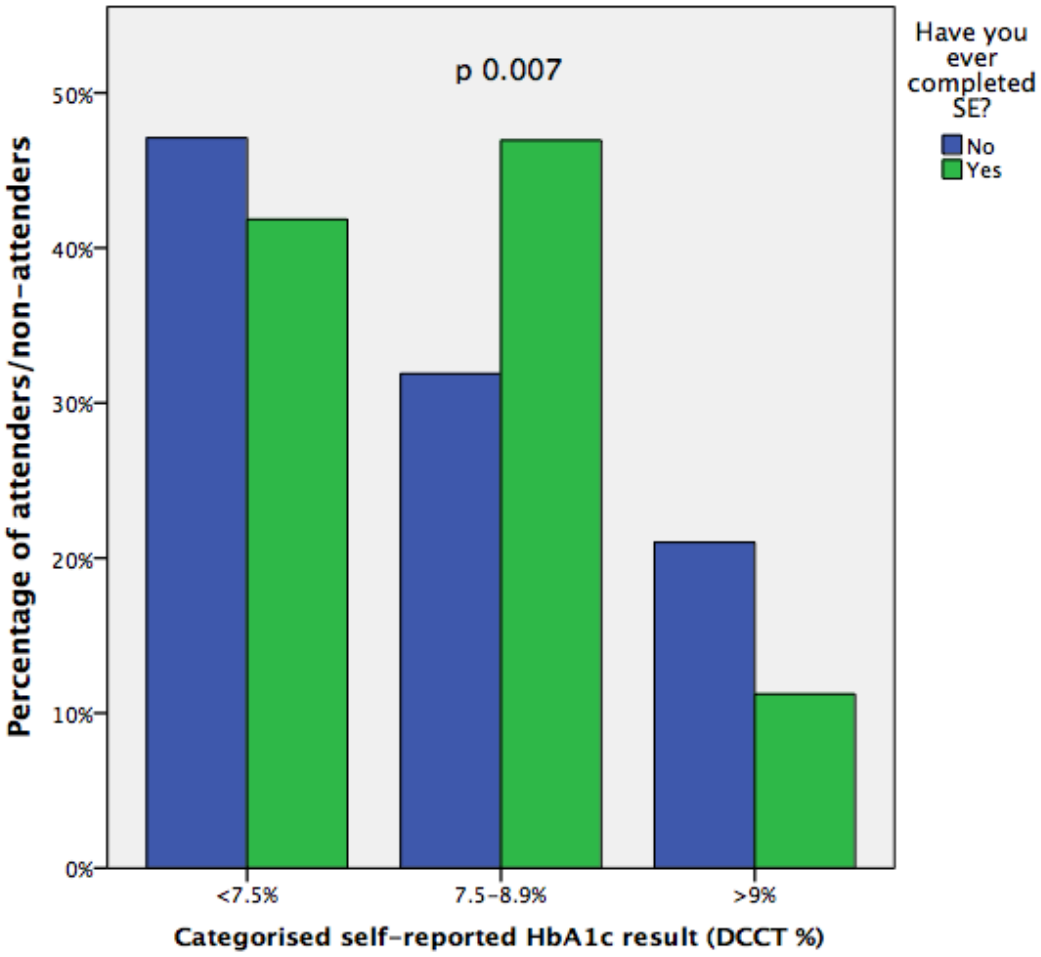
Variable	Study group	Non-Attenders	Attenders	P value
Number of Complications **n 476**	0.4 +/- 0.8 0 (0-1)	0.47 +/-0.92 0 (0-1)	0.34 +/-0.658 0 (0-1)	0.21
Any hypoglycaemia? Yes **n 469**	253 (54%)	108/221 (49%)	145/248 (58%)	0.037
Hypoaware[a] (n 344)	312 (90.7%)	180 (91.4%)	132 (89.8%)	0.71
Gold score	2 (1-3)	2 (1-3)	2 (1-2)	0.93
No Problematic hypoglycaemia **n 466**	442 (95%)	208 (94%)	234 (96%)	0.53
HbA1c knowledge				<0.001
Not familiar with test	13 (3%)	12 (6%)	1 (0.5%)	
Unknown result	118 (26%)	70 (32%)	48 (20%)	
Know result	334 (71%)	138 (62%)	196 (79.5%)	
<7.5%	147 (44%)	65 (45%)	82 (40%)	0.007
7.5-9%	136 (41%)	44 (33%)	92 (48%)	
>9%	51 (15%)	29 (22%)	22 (12%)	
HbA1c (DCCT%) **n 323[b]**	7.91% +/- 1.56 7.6% (7-8.3)	8.08 +/- 1.99 7.5 (7-8.6)	7.79 +/- 1.2 7.65 (7.1-8.2)	0.92
Benefit (n 443)				<0.001
HbA1c<7.5% & low risk problematic hypoglycaemia	126 (29%)	55 (26%)	71 (30%)	
HbA1c>7.5% or high risk problematic hypoglycaemia	191 (43%)	75 (36%)	116 (50%)	
No HbA1c knowledge	126 (28%)	78 (38%)	48 (20%)	

Impaired hypoglycaemic awareness (IHA) was assessed using the Gold score. There was no difference in Gold score between the groups (p=0.71). However, only people who had reported hypoglycaemic events in the previous question were asked to complete the Gold score. Therefore, only half of respondents completed the Gold score. A combination of hypoglycaemic events and Gold score was created to identify people with high risk of problematic hypoglycaemia (as outlined in 7.4.3.3). Combining these two questions produced fewer missing cases. Analysis of this new variable; *problematic hypoglycaemia,* remained non-significantly different between attenders and non-attenders.

There was no difference in number of complications (p=0.206) or diabetes duration (p=0.32) between the groups. HbA1c when treated as a continuous variable was the same across the two

groups. When categorised, according to Quality and Outcomes Framework (QOF) targets (<7.5%, 7.5-9% and >9%), there was a statistically significant difference as shown in Figure 11-5 (p=0.007) (NHS England, 2014). The survey relied entirely on self-reported data; 71% of respondents knew their HbA1c result. Analysis of categorical HbA1c, with lack of knowledge as a separate category increased the statistical difference between the groups (p<0.001).

Figure 11-5: Chart showing self-reported HbA1c categorised according to QOF targets for those that have and have not attended SE.
29% of respondents did not complete this question as they were either not sure of their result or were not familiar with the test. The results have been adjusted for this in Table 11-5.



An additional variable, *benefit*, was computed from the combination of categorised HbA1c knowledge or lack of and risk of problematic hypoglycaemia (as described in 7.4.3.3). Low benefit was defined as those with HbA1c <7.5% and low risk of problematic hypoglycaemia. The other group would potentially benefit from DAFNE (if not already attended) as they have either an HbA1c above 7.5% and/or a high risk of problematic hypoglycaemia. 29% of respondents fell into the low benefit category, almost half of whom had not attended SE (55 of 126 low benefit). There was a significant difference in benefit between the attenders and non-attenders (p<0.001), which is discussed in more detail below (11.10).

11.8 Open question responses

I led a small team in the coding of three open question responses:

- What do you think is the ONE biggest thing preventing you from coming to a self-management course?
- What do you think is the ONE biggest thing that would make it easier for you to attend?
- What was the ONE most important thing that encouraged you to attend DAFNE or similar self-management course?

The two other members of the team had little prior knowledge of diabetes education research or inequalities of access. One was a medical student and the other a service user who had attended DAFNE, bringing a different perspective to the analysis.

The nine-step process, described in Table 7-1, started with coding a selection of 25 anonymised open responses to "What do you think is the ONE biggest thing preventing you from coming to a self-management course?". These responses were read by each researcher, who initially created coding matrices individually. We then met to discuss our thoughts and reasoning behind our matrices. At this meeting a single matrix was adapted and agreed upon. We then used this matrix to code another selection of open responses. The codes were collated and discrepancies discussed, leading to further refinement of the matrix. This refinement was repeated until all members of the team were content with the coding matrix.

Previous description of the nine-step process stipulates use of the first tangible sentence and disposal of the rest of the data (Forbes et al., 2007, Feher Waltz C. et al., 1991). However, during the development of the coding matrix, we decided more context would add value to the analysis. Thus, the team was provided with all relevant open question responses. A sample was coded in this way and a comparison of the codes in the presence or absence of context assessed. Coding the data within context provided less inter-rater variation, therefore the team continued coding unblinded to other responses. The penultimate step involved individual team members using the coding matrix to code all data. I then combined these codes using Microsoft Excel. Inter-rater variability was assessed; the three team members showed an inter-rater variability of 5.55% (13 disagreements out of 234 open responses for question regarding biggest barrier to attendance) indicating adequacy of the coding matrix. Once the coding matrix was finalised, it was used to code all open question responses. The coding matrix for non-attenders is shown in Table 11-6 with data extracted from the survey included, to illustrate how the codes suited open questions about barriers and enablers.

Category	Sub-category	Example from question 'What do you think is the ONE biggest thing preventing you from coming to a self-management course?	Example from question 'What do you think is the ONE biggest thing that would make it easier for you/encourage you to attend?'
Attendee	Time Commitment	*I think the biggest thing is time.*	*Enough time to attend and the knowledge it would give me, I know it would be useful for the management of the disease.*[1]
	Work Commitment	*Time off work*	*If it was something employers legally had to give employees the time off to take the course.*
	Education Commitment	*Clashing with education…*	*Student*
	Family Commitment	*I'm a single parent.*	*Childcare; split over weeks or mornings only*
	Psychological (Denial)	*Fear. Don't want to talk in a group as find it distressing.*	*I am trying my best. I need help. Mental physical and emotional*
	Low Benefit (Knowledge)	*I have good diabetes management from self-learning.*	*I just don't feel I need it, but might come if I had the need*
	Low Benefit (Control)	*I think I manage to a reasonable level without attending a week long course…*	*A guarantee that my overall sugar level results would vastly improve and that the expertise was of the highest quality.*
Course	Physical Logistics	*Travel*	*The convenience of the venue.*
	Time Logistics	*Just never on when I'm not busy*	*Making it so I can attend 1-2 days each week*
	Regimen	*I only inject twice per day and wouldn't want to change.*	*Adapting the course so I can continue with my current scheme but get slightly better control.*
	Teaching style	*Groups of people would put me off*	*If it wasn't in a group then I'd be willing - I would prefer to find things for myself*
	Duration	*The length of the course.*	*If it was shorter course*
System	HCP advertising/marketing	*Not heard of it before*	*Give me more information about course which is accessible for me.*
	Organisation/Administration	*I have been put on a waiting list (at least I think I have) but have not heard anything - I would really like to attend one!*	*I have been put on a waiting list (at least I think I have) but have not heard anything - would love to attend!*
	Tailored Need (Honeymooners)	*I'm still in a honeymoon period.*	*I'm still honeymooning so I'm not ready to put the DAFNE training into practice. I will attend immediately after I stop honeymooning.*
	Tailored Need (Physical)	*Wheelchair bound, need transport*	-

Category	Sub-category	Example from question 'What do you think is the ONE biggest thing preventing you from coming to a self-management course?	Example from question 'What do you think is the ONE biggest thing that would make it easier for you/encourage you to attend?'
	Tailored Need (Learning Disability)	*I have learning disability and communication problems. I fear I would not understand what is course about.*	*It would have to be in easier language for me to understand*
Nothing			*Nothing that I can think of.*

Table 11-6: The coding Matrix used for survey, showing examples of open question responses for each category and sub-category.
The table illustrates how the same coding matrix was used for two different survey questions, and gives examples of how the different responses were coded under sub-category. Both questions included uncodeable/incomplete responses or responses such as 'nothing would encourage me to come'. These were coded as 'nothing'. [1] *shows an example of how using the first tangible answer given would affect coding.*

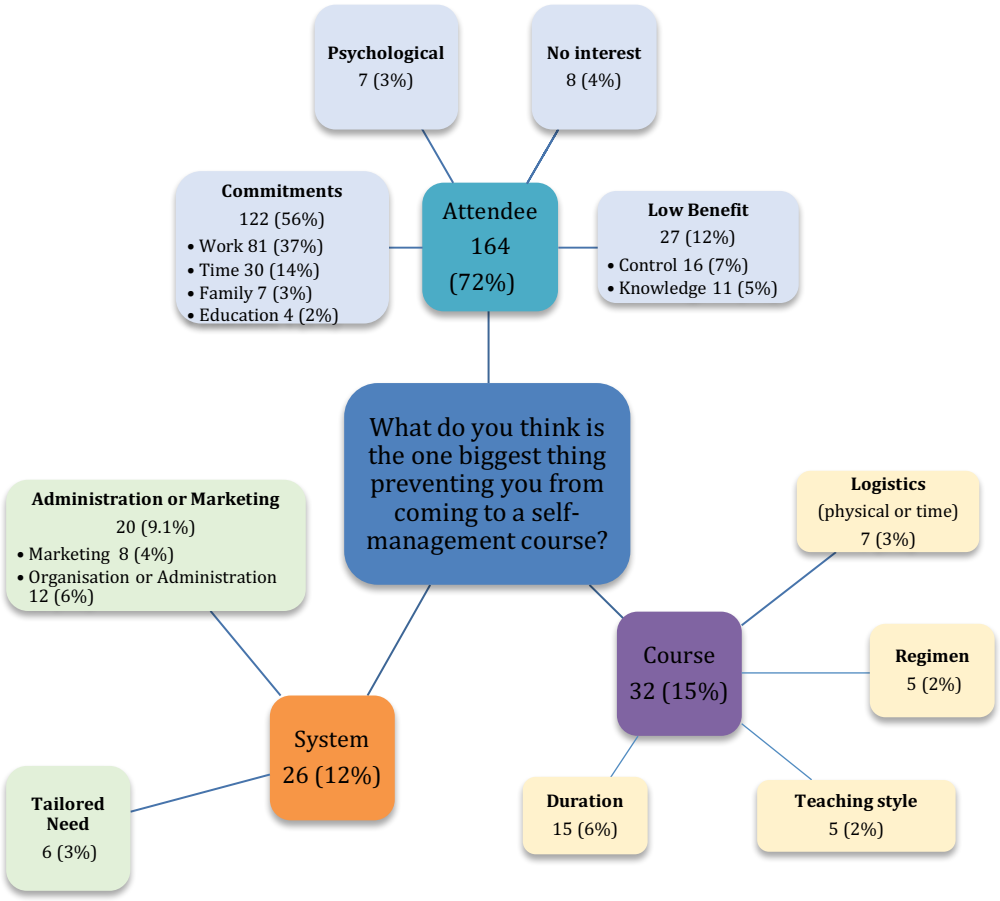
Further discussion and refinement of the coding matrix was required to accommodate responses from attenders, regarding motivators to attend SE (Table 11-7). This process was iterative and involved all three members of the team immersing themselves in the data, producing individual codes, lightly based on the previous coding matrix. Table 11-7 shows the initial version (v1) and the finalised version (v2). Input from the service user brought an interesting perspective, causing the coding to change particularly when considering 'control' and whether the wish for control of diabetes, was related to a desire for knowledge leading to empowered control of their diabetes, or a desire to control it in any way necessary to avoid longer-term complications. He also felt that some people may fully understand their diabetes, but choose not to control it for other reasons, such as denial. Hence control was moved to health, and divided into three subcategories. Additionally, there was too much inter-rater variability between the subcategories 'dietary freedom' and 'flexibility to eat or not'. This was therefore combined to dietary flexibility; being able to make a choice about when to eat/miss a meal, as well as what to eat.

Table 11-7: Table showing the iterative process of coding the open responses from attenders at SE about the motivators to attendance.
The over-arching categories did not change in the process, but there was refinement of the subcategories between v1 (version 1) and v2 (version 2)

Category	Sub-category (v1)	Sub-category (v2)
Knowledge	Understand diabetes	Understand & manage diabetes
	Control	-
	Nutrition	Nutrition
	Wanting to understand new regimen/CSII	Wanting to understand new regimen/CSII
Lifestyle	Dietary freedom	Dietary flexibility
	Activities	Activities
	Travel	Travel
	Flexibility to eat/not	-
Encouragement	Peer	Peer
	Family/friends (non-diabetic)	Family/friends (non-diabetic)
	DSN	DSN
	Diabetes doctor	Diabetes doctor
	Other HCP	Other HCP
Health	Concern about complications	Concern about complications
		Control - non-specified
	Problematic lows	Control - Problematic lows
	Problematic highs	Control - Problematic highs
Other	Route to CSII	Route to CSII
	Integrated into clinical pathway/not questioned	Integrated into clinical pathway/not questioned
	Uncodeable/nothing	Uncodeable/nothing

Figure 11-6 illustrates the proportion of respondents fitting into each category and sub-category for the barriers to attend SE. The most common barrier to attendance at SE was associated with commitment, with work being the most oft quoted sub-category. Fewer respondents felt there was either a problem with the course or the system.

Figure 11-6: Pictogram of categorised barriers to attendance at structured education with count and percentage of respondents.



Example quotes for each category are shown in Table 11-8. These examples help to illustrate the difficulties faced with differentiating between codes; particularly time commitment versus duration of the course. The former was felt to be an attendee issue because they were unable to prioritise the time, or as our service user researcher eloquently described, not have 'the luxury' of being able to attend because of other commitments. It also illustrates how understanding the context helped with coding; the quote in physical logistics '*Not able to afford it. On very limited income'* was followed by the suggestion for improvement as *'provision of a bus pass*'. Another point that we spent time discussing was when does a lack of interest denote denial of disease? We did not want to make assumptions from a sentence describing a lack of interest, and therefore coded them as uninterested, as it was important to note an answer was given rather than missing data.

Category	Sub-category	Quote
Attendee n 164 72 %	Time Commitment 30 (14%)	*Time during the week* *Time required - week is too long*
	Work Commitment 81 (37%)	*Not interested/busy at work* *Time/work I do shift work. In addition, as a nurse I feel that I have additional understanding of adjusting insulin doses/carbohydrate counting etc.* *The amount of time it will take and the fact that it's during work hours* *5 days is too long out of the office. I cannot use vacation as I have children. I would not feel comfortable requesting additional paid or unpaid leave.* *I have to take a holiday to attend.*
	Education Commitment 4 (2%)	*The fact is a 5-day course consecutively. Don't have time because of university. Maybe specific day or two each week instead of 5 consecutive days*
	Family Commitment 7 (3%)	*Recently becoming a father* *Childcare. My husband can't take five mornings off to take the children to school and I feel that it is a big ask to get someone else to look after my kids for a week.*
	Psychological (Denial) 7 (3%)	*I don't like talking about my diabetes, I wouldn't want to share all my experiences* *Fear. Don't want to talk in a group as find it distressing.*
	Low Benefit (Knowledge) 11 (5%)	*Feel like I'm already speaking with enough professionals about my diabetes and general health* *Doubt that after living with type 1 diabetes for so long that I would learn sufficient knowledge to warrant such a time commitment.*
	Low Benefit (Control) 16 (7%)	*I have good diabetes control and haven't felt the return would be worth the time commitment. My specialist also supported this view* *Don't really need it - my control/understanding in generally very good*
	Uninterested 8 (4%)	*I'm not interested*

Category	Sub-category	Quote
		Nothing is preventing me from going to a self-management course - I just don't want to
Course **n 32** **15%**	Physical Logistics 5 (2%)	*Wheelchair bound, need transport* *Not able to afford it. On very limited income.*
	Time Logistics 2 (1%)	*Just never on when I am not busy*
	Regimen 5 (2%)	*I only inject twice per day and wouldn't want to change.* *Achieving good control with Novomix 30 Penfill in the morning, and Novorapid Penfill and Insulatard Penfill in the evening. Not keen on injecting several times a day.*
	Teaching style 5 (2%)	*Groups of people would put me off* *Can't be bothered to have a lesson for a week - I'm already a student, more lessons!*
	Duration 15 (6%)	*The length of the course.* *The fact it takes five days to achieve this.*
System **n 26** **12%**	HCP advertising or marketing 8 (4%)	*Not heard of it before* *I am free to come any time* *Never being ask*
	Organisation or Administration 12 (6%)	*The lack of availability coupled with my schedule changing at short notice. One course was also cancelled due to staffing shortages.* *I have been put on a waiting list (at least I think I have) but have not heard anything - I would really like to attend one!* *I keep getting letters reminding me to go but it asks me to phone for appointment and I keep forgetting*
	Tailored Need (Honeymooners) 2 (1%)	*I'm still in a honeymoon period.*
	Tailored Need (Physical) 1 (1%)	*Not physically able to make the five days*
	Tailored Need (Learning Disability) 3 (1%)	*I have learning disability and communication problems. I fear I would not understand what is course about.* *May forget bad memory*

Table 11-8: Table showing the categories and subcategories used for open responses from non-attenders. The quotes in the right-hand column show data taken from the open responses to 'What do you think is the ONE biggest thing preventing you from coming to a self-management course?'. Count (percentage of non-attenders) of respondents for each category and sub-category are shown.

Respondents who had attended SE were asked “What was the ONE most important thing that encouraged you to attend DAFNE or similar self-management courses?”. Their responses were coded using the iterative manner described in Table 7-1. Six main categories (see Table 11-9) were identified with knowledge (38%); including the subcategories of understand and manage diabetes, nutrition and understand new regimen (including CSII) being the most often quoted as the motivator for attendance. This was followed by health (26%) which included subcategories of concern about complications and control (specifically glycaemic control but without mention of requiring skills to achieve this), problematic hypoglycaemia or problematic hyperglycaemia

Category	Sub-Category	Quote
Knowledge **n 100** **38%**	Understand and Manage T1DM 76 (29%)	Committed to getting the best knowledge about T1 to lower my HbA1c. To further expand my knowledge on the condition that is diabetes and to help me how to gain tighter/better control and maintaining it.
	Nutrition 5 (2%)	Improving blood sugar control by better understanding how to eat!
	Understand new regimen 19 (7%)	To calculate the correct insulin doses to carbohydrate portions as I only switched to analogue insulins in 2007 and I was unsure of the insulin units I needed for each carbohydrate portion/meals. I wanted to get onto a pump because my sugars were up and down
Lifestyle **n 23** **9%**	Dietary flexibility 20 (8%)	More freedom and flexibility More freedom/choice over what I ate
	Living life 3 (1%)	My blood sugar level was getting out of control so one of the most important things that encouraged me then was the flexible lifestyle it afforded me. Being abled, to adjust dosage, and eating for exercise
Encouragement **n 45** **17%**	Peers 7 (3%)	I was told I should attend by a friend Strong recommendations from other diabetics.
	Friends and Family 1 (0%)	My boyfriend at the time
	DSN 11 (4%)	DSN recommendation/endorsement My control was getting worse and it was recommended by your diabetes nurse
	Diabetes doctor 15 (6%)	Doctor suggested I should (at secondary care). My consultant's recommendation
	Other HCP 11 (4%)	Nutritionist & doctor at X diabetes clinic recommended it following numerous high HbA1c results.

Health **n 68** **26%**	Concern about complications 15 (6%)	I am now a bit older and looking to my future so I felt that it was time take my health seriously and not put off coming to the course. Concern over HbA1C and the possibility of long term complications
	Control – non-specified 39 (15%)	Loss of control Better control of blood sugar levels
	Control – problematic hypoglycaemia 11 (4%)	I was having many hypos every day and wanted to know how I could improve this. I wanted increased hypo awareness + less hypos
	Control – problematic hyperglycaemia 3 (1%)	I felt very ill and confused about how to manage the situation. I had very high blood glucose and ketones. I had a number of urine infections. High blood sugar levels (difficult control)
Clinical Pathway **n 9** **3%**	Integrated into pathway/not questioned 9 (3%)	Referral from clinic It was at a convenient time and did not interfere with my work commitments Having time, post retirement from work to be able to attend without using annual leave or taking other time off which could have triggered sickness absence procedures and harmed by reputation
Un-codeable **n 18 (17%)**		

Table 11-9: Table of categories and sub-categories for motivations to attend SE, with quotes to provide context for each sub-category.
Number (n) of respondents and percentage (%) of total attenders at SE shown.

Table 11-9 shows the categories and sub-categories allocated to example open responses taken directly from survey responses for attenders regards their motivation to attend SE. Some of the coding proved problematic for particular cases. For example, there was a degree of overlap between 'understand and manage T1DM' (knowledge) and 'control – non-specified' (health). We coded responses that did not mention the need for knowledge to control their diabetes or blood sugars as the later, whilst the former required specific identification of the need for knowledge to empower them to self-manage their disease.

Figure 11-7: Word frequency pictogram/word cloud for non-attender responses to open response questions. Questions included: "What do you think is the ONE biggest thing preventing you from coming to a self-management course?"[B], "What do you think is the ONE biggest thing that would make it easier for you/encourage you to attend?"[C], "other factors that you feel make it difficult/discourage you from using the DAFNE course"[D] and combination of the first 2 questions[A]. The size of a word represents the frequency with which it occurred in the data.

The word frequency pictograms used raw data from the non-attender open question responses. They showed overlap between the frequently occurring words (font sized is associated with frequency) and our generated themes; work, timing, time, evening, course, shorter, weekend, online and commitments. The pictograms served to ensure there were no newly occurring themes, that had been missed in the development of the coding matrix. Although numerical analysis was not carried out, the pictograms broadly corroborated the identified themes and validated our translation of the open questions into the coding matrix.

11.9 Multivariate analysis

Table 11-10 illustrates all variable with p value <0.2 in the univariate analysis to be considered for entry into the multivariate analysis. Those with co-linearity were excluded such as scheduled service use; where co-linearity was assumed as the pathway for referral to DAFNE includes a consultation in secondary care. Other variables thought to have a high chance of co-linearity based on previous research or logic were checked for correlation before entrance into the exploratory model (Appendix M).

Numeracy (SNS), health literacy and educational attainment (categorised into primary school, secondary school or university level) were checked for correlation. There was significant correlation between numeracy and educational attainment (correlation coefficient 0.416, $p<0.001$). Numeracy was less significant than educational attainment in univariate analysis ($p=0.001$ vs $p<0.001$); therefore, it was excluded from the multivariate analysis. Health literacy did not reach a correlation coefficient of >0.4 with numeracy (coefficient 0.3 $p<0.001$) or educational attainment (correlation coefficient 0.24 $p<0.001$), so was included in the multivariate analysis.

Significant correlation was found between spoken English ability and being born in the UK (correlation coefficient 0.646, $p<0.001$). Spoken English ability was less significant than being a UK national in univariate analysis ($p=0.059$ vs $p=0.003$), so was removed from the multivariate analysis. Ethnicity did not show sufficient correlation with English language ability (correlation coefficient 0.2) or UK national (correlation coefficient -0.27) to warrant removal from multivariate analysis.

Table 11-10 outlines variables excluded, with explanation, and for those included the number of missing cases per variable. Variables with more than 30 missing cases were modified (as per 7.4.3.4) to allow their inclusion in the analysis. After categorisation, the new variable was checked for missing cases and appropriate univariate analysis was carried out to ensure significance remained unchanged (despite modification). The number of missing cases within each new variable were measured and reported within Table 11-10.

Table 11-10: Variables considered for inclusion in the multivariate analysis.
Table shows reasons for exclusions of variables, the number of missing cases and any modification made to variables prior to inclusion in multivariate analysis. New categorical variables underwent univariate analysis to ensure statistical significance had not been lost by categorisation. For each new variable, the p values and number of missing cases are shown in parenthesis.

Variable	Number missing	Alternative/Categorisation of variable for use in multivariate model
Gender	17	
Ethnicity	16	Categorised into white, black, Asian, other
Born in UK	18	
Education level	10	
English language		Removed due to correlation with nationality & ethnicity
Health Literacy	9	
SNS		Removed due to correlation with educational ability
Number of sources of advice	6	
Insulin regimen		Not included as certain regimens likely to be associated with attendance at SE as a requirement of course (MDI BD or CSII use)
Attending Secondary care (& other scheduled service use data)		Not included as part of the pathway to access SE includes a consultation in secondary care, so highly likely to be associated
PHQ2	89	Categorised to depression as 7.4.2.2 (p 0.209 with 28 missing cases).
Number of admissions	36	Categorised to binary variable (Yes/No/Missing (p 0.104))
Hba1c result	173	}30% of respondents didn't know their result, and }therefore skipped this questions so knowledge and self-reported result was combined and categorised. The new variable, HbA1c knowledge and result, remained significant (p<0.001) with fewer missing cases (31).
HbA1c knowledge	13	
Hypoglycaemia events	27	
Positive HCP message	73	Categorised to positive message (>3 (neutral)), less than positive (<4) and missing (p <0.001)
Employment	9	

Forward Wald binary regression model exploring relationship with attendance at SE found four explanatory variables (see Table 11-11). A goodness of fit test was carried out. The model was well calibrated, not a chance finding (Hosmer and Lemeshow test; Chi^2 7.723, df 4, p 0.46) with the four variables predicting between 17 to 23% of the variance (Cox & Snell R^2 0.17, Nagelkerke R^2 0.23) Sensitivity analysis was carried out as described in 7.4.3.4 and found the same explanatory variables to be significantly associated with attendance at SE (Appendix N).

Table 11-11: Results of exploratory regression analysis showing the explanatory variables associated with attendance at SE. Statistical significance taken as <0.05. [a] Reference group

Variable	Odds Ratio	CI	p value
Strength of HCP message about SE			
≤3 (neutral)[a] versus >3 (positive)	2.77	1.54 – 5.01	0.001
HbA1c knowledge or result			0.004
<7.5%[a]			
7.5 – 9%	1.83	1.06 – 3.14	0.03
>9%	0.67	0.32 – 1.43	0.3
Do not know result	0.63	0.36 – 1.1	0.11
Not familiar with this test	0.41	0.04 – 3.78	0.43
Educational attainment			
At least University[a]			0.008
Secondary school	0.49	0.3 – 0.81	0.005
Primary school or less	0.17	0.02 – 1.5	0.1
Gender (Female[a]**)**	0.56	0.36 – 0.86	0.009

The binary regression model (shown in Table 11-11) found the strength of message about SE received from the care provider was the variable most strongly associated with attendance. Receiving a positive message about SE almost tripled the chance of having attended SE (OR 2.77 CI 1.54-5.01 p=0.001). Glycaemic control was associated with SE, with an HbA1c of 7.5% - 9%, compared to HbA1c < 7.5%, almost doubling the likelihood of having attended SE (OR 1.83 CI 1.06-3.14 p=0.03). Although not statistically significant, people with HbA1c >9% and those unable to report their HbA1c result (due to lack of knowledge) were half as likely to have attended SE when compared to those with HbA1c <7.5% (see Table 11-11). The third variable associated with attendance at SE was educational attainment, with people completing secondary school being half as likely to attend than those with university or equivalent qualifications (OR 0.49 CI 0.3-0.81 p=0.005). A primary school level achievement or less was non-significantly associated with reduced likelihood of attendance (OR 0.17 CI 0.02-1.5 p=0.1). Lastly male gender almost halved the likelihood of attending SE (OR 0.56 CI 0.36-0.86 p=0.009).

11.10 Subset analysis

Further exploratory analysis was carried out on the four variables identified in the regression analysis as being associated with attendance at SE. Only respondents who had not attended SE were included in this subset analysis to further explore the explanatory variables.

11.10.1 Heard of SE and strength of message

A composite variable was produced by combining responses to the question about if the respondent had heard of SE before becoming involved in the study and how positive their healthcare

professional had been about SE. Two groups were produced, those who had heard of SE and received a positive message about it, and those that had either not heard of SE or had received a negative message from their HCP about it. If a respondent had said that they had not hear about SE, but gave a score (1-5) to their healthcare professional this score was discounted and their first response (not heard of SE) taken. This was the case for 24 respondents, out of 161 respondents who had both heard of SE and provided a score for their HCPs message. 55% (118) of non-attenders had heard of SE and received a positive message about it. 24 (25%) people had not heard of SE and the remainder (72 (75%)) reported receiving a negative message.

Table 11-12: Univariate subset analysis of those not attending SE according to strength of message from HCP and hearing of SE.
Potential benefit from SE composed of HbA1c and risk of hypoglycaemia (based on presence of hypoglycaemic events and Gold score). Impaired hypoglycaemic awareness based on Gold score. Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only. Categorical data reported as count and percentage. Adjusted statistical significance taken as $p < 0.003$.

Variable	Heard of SE and Positive message (n 118 (55%))	Not heard or less than positive message about SE (n 96 (45%))	p value
Age (years)	34 (27-45)	42 (31-55)	0.018
Gender (male) **n 183**	73 (63.5%)	70 (74.5%)	0.089
Ethnicity (white) **n 210**	93 (80.2%)	69 (73.4%)	0.59
Born in the UK (yes) **n 210**	87 (75%)	55 (59%)	0.011
English language			0.052
1st Language	103 (88%)	73 (77%)	
2nd language fluent	12 (10%)	13 (14%)	
Conversational or less	2 (2%)	9 (9%)	
Educational attainment			0.004
Primary school or less	1 (1%)	10 (11%)	
Secondary school	40 (35%)	36 (39%)	
At least University	76 (65%)	46 (50%)	
Confidence in filling forms	5 (4-5) 4.59 +/- 0.76	5 (4-5) 4.36 +/- 1	0.004
SNS	4.75 (4.13-5.38) 4.62 +/- 1.1	4.75 (3.63-5.25) 4.34 +/- 1.3	0.004
Sources of diabetes advice	2 (1-3) 2.57 +/- 1.44	2 (1-3) 2.18 +/- 1.15	0.019
PAID	5 (2.5-10)	2.5 (1.25-10)	0.055
CIDS	68 (56-74.5)	64 (55.25-74.75)	0.140
Duration of diabetes (years)	17 (8-26)	16.5 (10.5-25.5)	0.537
Admissions (number of days)	0 (0)	0 (0)	0.921
Total use of services	9 (4.25-15)	5 (4-10)	0.001

Variable	Heard of SE and Positive message (n 118 (55%))	Not heard or less than positive message about SE (n 96 (45%))	p value
Hypoaware (Gold score <4) n 138	70 (90%)	57 (93.4%)	0.755
HbA1c knowledge & result n 202			0.006
Not familiar	2 (2%)	9 (10%)	
Don't know result	31 (27%)	32 (36%)	
>9%	20 (18%)	6 (7%)	
9-7.5%	27 (24%)	13 (15%)	
<7.5%	33 (29%)	29 (33%)	
Potential benefit			0.008
HbA1c<7.5% & low risk problematic hypoglycaemia	28 (26%)	26 (31%)	
Hb1c>7.5% or high risk problematic hypoglycaemia	48 (44%)	19 (23%)	
No HbA1c knowledge	33 (30%)	38 (46%)	
Subcategory of barrier			0.05
Commitments	69 (63%)	45 (50%)	
Course requirement	16 (15%)	12 (13%)	
Admin/Marketing	5 (5%)	10 (11%)	
Low Benefit	8 (7%)	18 (20%)	
Psychological	5 (5%)	2 (2%)	
Tailored need	3 (3%)	3 (3%)	
No interest	4 (4%)	1 (1%)	

Bonferroni adjustment was made to the significance level, to account for the exploratory nature of the analysis. This changed the critical significance level from 0.05 to 0.003 (Bland and Altman, 1995, MedCalc). The only statistically significantly different variable was the total use of services, with those receiving a negative message having less contact or input from HCPs. Although non-significant there was a trend towards older age (p=0.018), lower educational attainment (p=0.004), lower numeracy and lower health literacy in the group receiving a negative message about SE (p=0.004 & p=0.004 respectively).

11.10.2 Benefit – based on HbA1c and risk of problematic hypoglycaemia

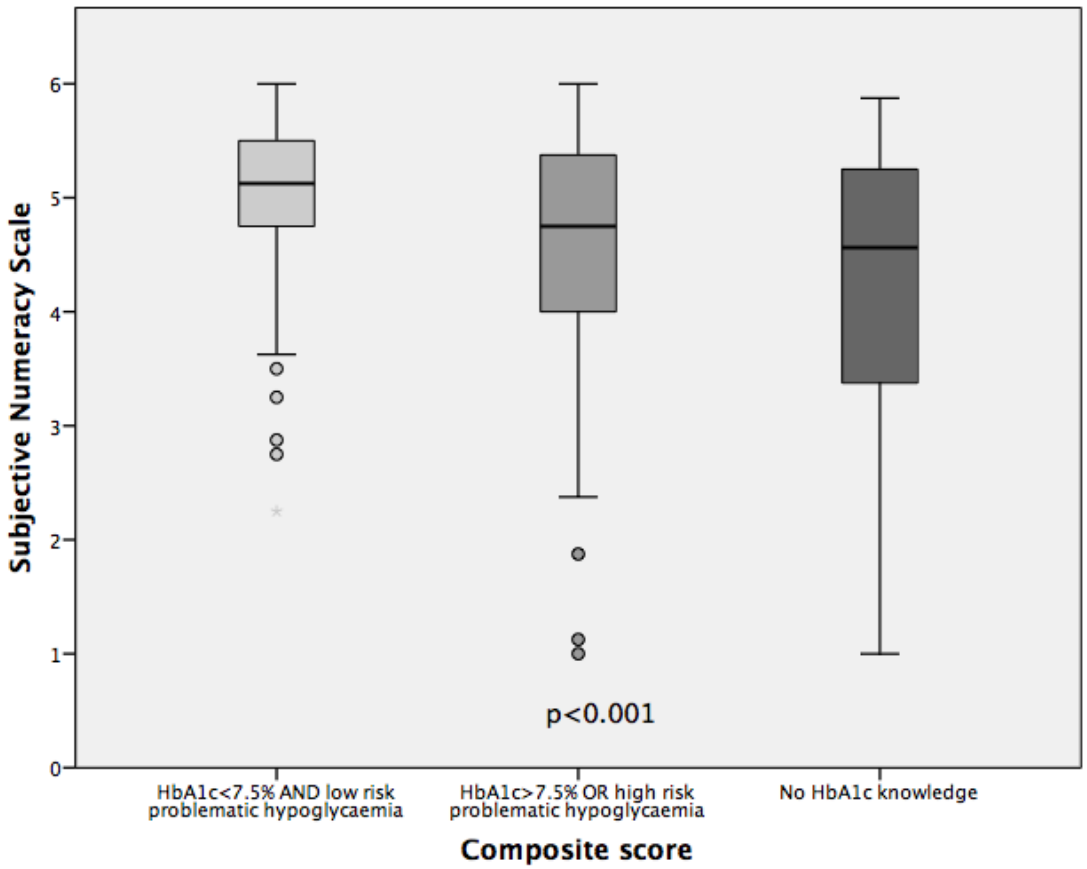
Table 11-13: Univariate subset analysis of those not attending SE according to self-reported categorical HbA1c and risk of hypoglycaemia (based on previous events and gold score).
Median and inter-quartile range (IQR) shown for continuous data. Mean shown for illustrative purposes only where indicated. Categorical data shown as count and percentage (%). Adjusted statistical significance taken as p value <0.002.

Variable	<7.5% & low risk (n55)	>7.5% or high risk (n75)	Don't know result (n78)	P value
Age	40 (31-50)	33 (25-47.5)	40 (24.2-54)	0.017
Gender (male)	39 (28%)	43 (31%)	57 (41%)	0.076
Ethnicity (white)	48 (87%)	59 (79%)	54 (69%)	0.232
Born UK (yes)	36 (65%)	60 (80%)	49 (63%)	0.05
Employment				0.015
Employed	34 (64%)	46 (62%)	44 (56%)	
Self-employed	11 (21%)	4 (5%)	5 (6%)	
Unemployed	1 (2%)	10 (14%)	14 (18%)	
Studying	1 (2%)	6 (8%)	7 (9%)	
Caring	0 (0%)	3 (4%)	3 (4%)	
Retired	6 (11%)	5 (7%)	5 (6%)	
Education				<0.001
University or above	49 (89%)	39 (53%)	30 (39%)	
Secondary school	6 (11%)	34 (46%)	38 (49%	
Primary school or less	0 (0%)	1 (1%)	9 (12%)	
Confidence in form filling	5 (5)	5 (4-5)	5 (4-5)	0.001
SNS	5.1 (4.7-5.5)	4.8 (4-5.4)	4.5 (3.4-5.3)	<0.001
Sources of diabetes advice	3 (2-4)	2.5 (1-3)	1 (1-3)	<0.001
Percent non-NHS source	33.3 (0-50)	0 (0-33)	0 (0-33)	0.039
CIDS	71 (62-75.5)	62.5 (54.3-72)	63.5 (55.8-74.3)	0.02
Depression (yes) n199	16 (19%)	32 (38.1%)	36 (42.9%)	0.127
PAID	2.5 (0-6.3)	5.63 (2-5-10.9)	5 (7.5)	0.02
SSRALS	0.25 (0-0.8)	0.25 (0-1.1)	0.25 (0-1)	0.360
QoL	8 (7-8.8)	8 (5.3-8)	7 (6-8)	0.233
Duration of diabetes (years)	22 (12-29.8)	17.5 (10-27.5)	14 (8-23)	0.034
Insulin use				0.013
MDI OD	28 (51%)	37 (50%)	32 (44%)	
MDI BD	19 (35%)	18 (24%)	24 (33%)	
CSII	1 (2%)	9 (12%)	0 (0%)	
Other	7 (12%)	10 (14%)	17 (23%)	
Total use of services	6 (4-12)	10 (6-15)	6 (3-12)	0.016
Attending 2nd care (yes)	43/52	50/59	48/63	0.087
Complications	0 (0-1)	0 (0-1)	0 (0-1)	0.55
Any sick days (yes)	0(0) 3.10 +/- 14.6	0(0-3) 3 +/- 5.75	0(0-3) 10.9 +/- 45	0.019
Any admissions (yes)	0 (0) 0.04 +/- 0.19	0 (0) 0.4 +/- 1.79	0 (0) 0.19 +/- 0.48	0.048

Variable	<7.5% & low risk (n55)	>7.5% or high risk (n75)	Don't know result (n78)	P value
Subcategory of barriers				0.045
Commitments	26 (49%)	38 (55%)	46 (62%)	
Course requirement	5 (9%)	11 (16%)	11 (15%)	
Admin/Marketing	2 (4%)	7 (10%)	8 (11%)	
Low Benefit	14 (26%)	8 (12%)	3 (4%)	
Psychological	1 (2%)	2 (3%)	2 (3%)	
Tailored need	3 (6%)	0 (0%)	1 (1%)	
No interest	2 (4%)	3 (4%)	3 (4%)	

Fifty-five (26%) people achieved an HbA1c<7.5% and had low risk of problematic hypoglycaemia in the non-attender group. After adjustment for multiple variables, four remained significantly different between the three groups. Those with likely low benefit had a higher level of educational attainment (p<0.001), reflected in the difference in health literacy and SNS scores (p=0.001 & p<0.001) (Figure 11-8). There was a trend towards this group being British nationals (p=0.05) who were older with a longer duration of diabetes (p=0.017, p=0.034). There was also a trend towards higher rates of employment and self-employment in the group less likely to benefit from SE, although this was not significant.

Figure 11-8: Subset analysis of those not attending SE; Box and whisker plot of subjective numeracy score (lower score being associated with lower levels of subjective numeracy) according to potential benefit from SE. The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the results with outliers illustrated individually with star or circle.



Those with likely low benefit used significantly more sources of advice about their diabetes. Although not significant after adjustment, there was a trend towards a lower use of services (p=0.016) and fewer days off sick (p=0.019) despite similar proportions attending secondary care amongst the low benefit group. There was no difference in psychological scores, although PAID and CIDS showed a non-significant trend to higher self-efficacy and lower distress in the group unlikely to benefit from SE.

Figure 11-9: Subset analysis of those that not attending SE according to potential benefit from SE. Bar chart illustrating the percentage of those with low to high benefit of SE (based on composite score of HbA1c and hypoglycaemia risk) according to their reported barrier to attendance at SE.

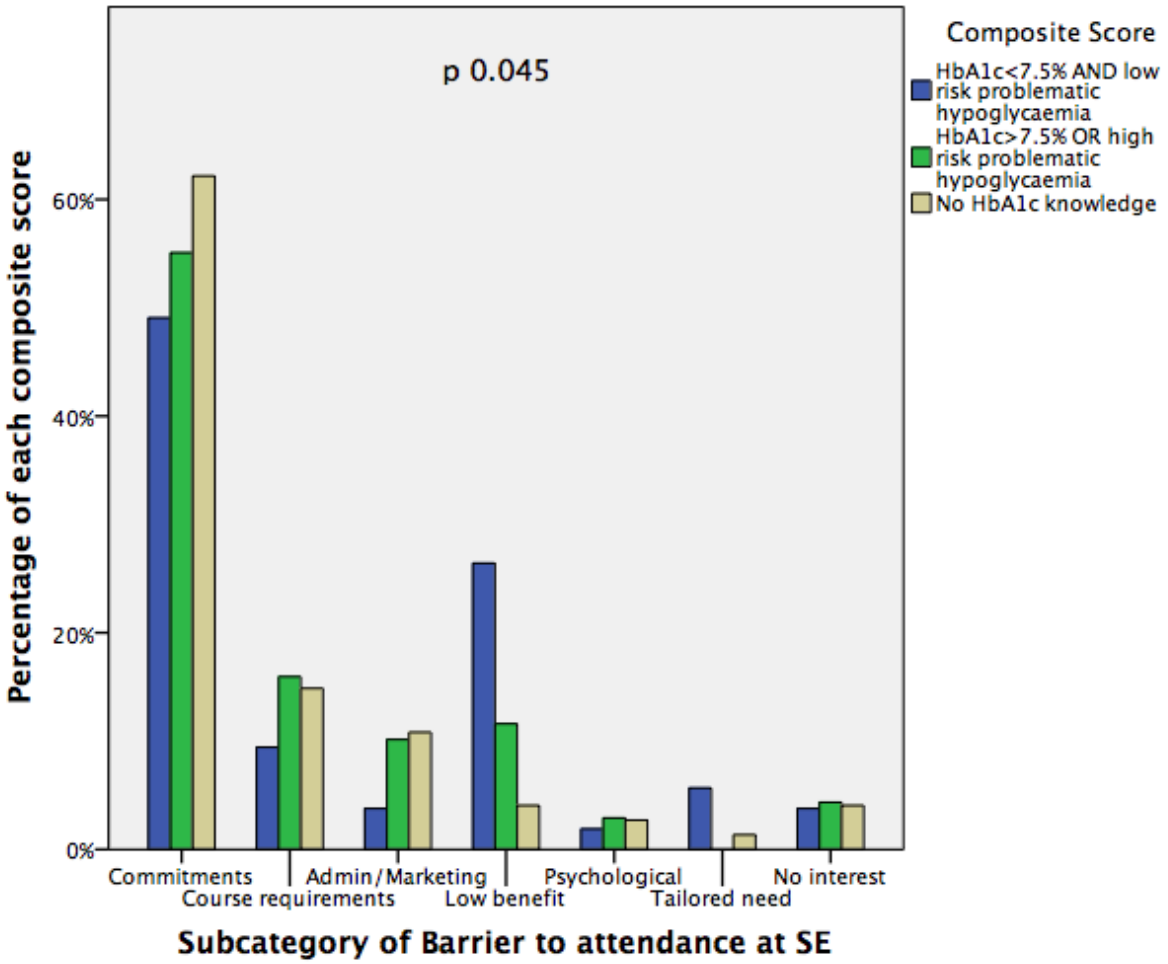


Figure 11-9 illustrates the barriers to SE quoted by the three groups according to potential benefit from SE (p=0.045). Those with probable low clinical need for SE fell into two main categories; tailored need (6% vs 0% and 1%) and perceived low benefit (26% vs 12% and 4%). The tailored need group includes people who are honeymooning (recently diagnosed with some preserved c-peptide function). Fourteen (26%) people with low clinical benefit from SE perceive low benefit themselves. It may be valuable to note that those who do not know their HbA1c result are more likely to quote time commitments as the barrier to attending SE (49% vs 55% vs 62%).

11.10.3 Educational Attainment

Table 11-14: Univariate subset analysis of those not attending SE according to educational attainment. Median and Inter-quartile range (IQR) shown for continuous variables. Mean shown for illustration purposes only. Categorical data reported as count and percentage. Adjusted statistical significance taken as p <0.002.

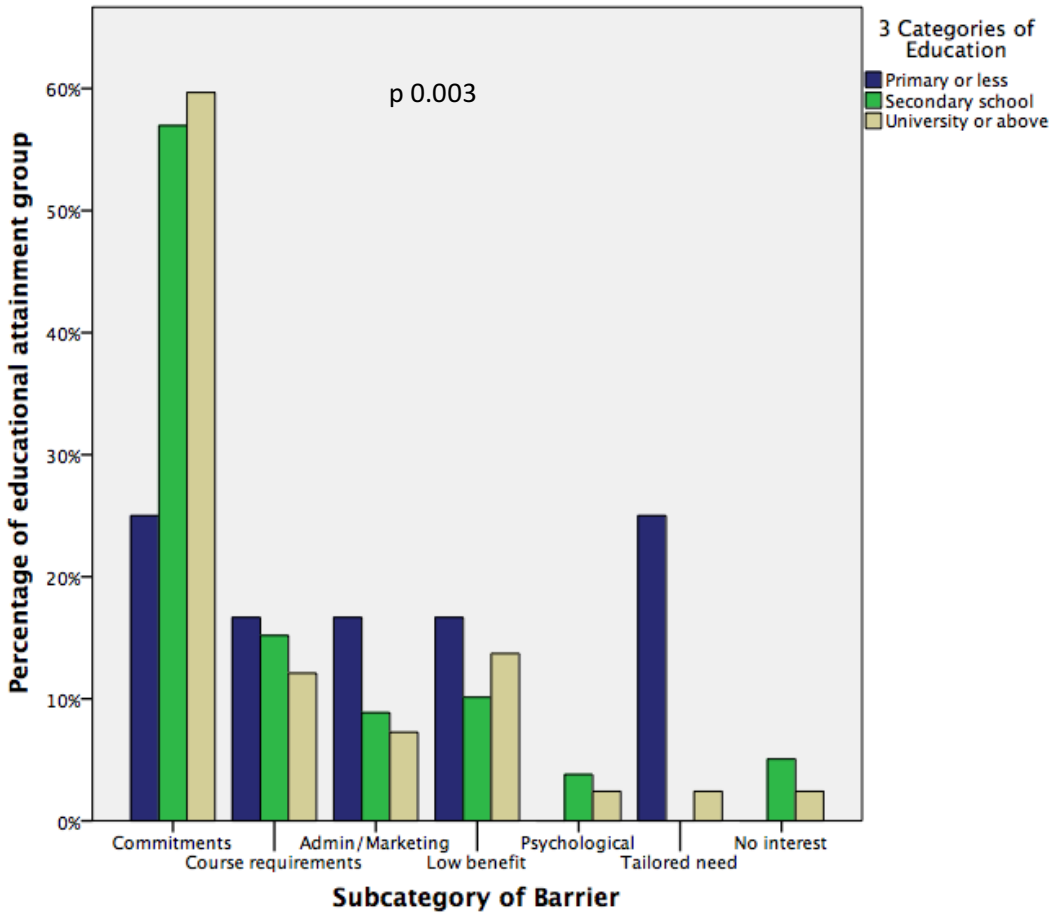
Variable	Primary school or less (n13 (6%))	Secondary school (n 86 (37%))	University or more (n 129 (55%))	p value
Age	54 (37.5-64.3)	41.6 (28-54)	34 (28-44.8)	0.003
Gender (male)	9 (69%)	62 (73%)	76 (61%)	0.211
English language				<0.001
1st language	9 (75%)	72 (83%)	108 (84%)	
2nd language fluent	0 (0%)	12 (14%)	16 (12%)	
Less than conversation	3 (24%)	2 (2%)	5 (4%)	
Born UK (yes)	6 (46%)	67 (79%)	81 (65%)	0.018
Marital status				0.001
Married	3 (25%)	33 (39%)	67 (54%)	
Divorced	3 (25%)	9 (11%)	2 (2%)	
Widowed	1 (8%)	1 (1%)	1 (1%)	
Single	5 (42%)	41 (49%)	54 (43%)	
Ethnicity (white)	5 (38.5%)	62 (72.9%)	106 (84.8%)	0.007
Employment				<0.001
Employed	1 (8%)	42 (49%)	92 (71%)	
Self-employed	0 (0%)	8 (9%)	14 (11%)	
Unemployed	7 (54%)	14 (16%)	6 (5%)	
Studying	1 (8%)	9 (11%)	6 (5%)	
Caring	1 (8%)	4 (5%)	3 (2%)	
Retired	3 (23%)	8 (9%)	6 (5%)	
Confidence in filling forms	2.5 (1.3-4)	5 (4-5)	5 (4.5-5)	<0.001
SNS	1.5 (1.1-3.4)	4.25 (3.1-5)	5 (4.6-5.5)	<0.001
Sources of diabetes advice	2 (1-2)	2 (1-3)	2 (1-3)	0.143
Percent non-NHS sources	0 (0)	0 (0-27)	20 (0-50)	0.001
CIDS	58 (43.5-69.5)	64 (56-75)	68 (59-74)	0.127
Depression (yes)	6 (54.5%)	43 (53.8%)	39 (31.7%)	0.005
PAID	7.5 (2.5-11.3)	5.62 (1.3-11.6)	3.75 (1.25-7.8)	0.205
SSRAL	1.5 (0.8-2.3)	0.29 (0-1.5)	0.25 (0-0.8)	0.003
QoL	6 (2-7)	7 (5-8)	8 (7-8)	<0.001
Duration of diabetes	15 (14-24.5)	16 (8-27)	17.5 (8.3-27)	0.996
Complications (yes)	6 (54.5%)	51 (60%)	98 (79.7%)	0.001
Insulin use				0.032
MDI OD	4 (36%)	37 (46%)	61 (50%)	
MDI BD	2 (18%)	23 (29%)	41 (33%)	
CSII	0 (0%)	2 (3%)	8 (7%)	
Other	5 (46%)	18 (22%)	13 (10%)	
Hypoaware (yes) (n144)	3 (60%)	40 (89%)	87 (93%)	0.053

Variable	Primary school or less (n13 (6%))	Secondary school (n 86 (37%))	University or more (n 129 (55%))	p value
HbA1c knowledge & result				<0.001
Not familiar	4 (33%)	7 (9%)	0	
Don't know result	6 (50%)	32 (39%)	31 (25%)	
>9%	0	21 (26%)	8 (7%)	
9-7.5%	2 (17%)	14 (17%)	27 (22%)	
<7.5%	0	8 (10%)	57 (46%)	
Total use of services	18.5 (7.3-24.5)	6 (4-12)	7 (4-12)	0.062
Sick days	4 (0-5)	0 (0-3)	0 (0-1)	0.001
Number of admissions	0 (0-1) 0.55 +/- 0.69	0 (0) 0.34 +/- 1.69	0 (0) 0.1 +/- 0.35	0.001
Subcategory of barriers				0.003
Commitments	3 (25%)	45 (57%)	74 (60%)	
Course requirement	2 (17%)	12 (15%)	15 (12%)	
Admin/Marketing	2 (17%)	7 (9%)	9 (7%)	
Low Benefit	2 (17%)	8 (10%)	17 (14%)	
Psychological	0 (0%)	3 (4%)	3 (2%)	
Tailored need	3 (25%)	0 (0%)	3 (2%)	
No interest	0 (0%)	4 (5%)	3 (2%)	

Different levels of educational attainment achieved significantly different SNS and health literacy scores (both p<0.001). Different levels of educational attainment were also associated with other factors often attributed to the social gradient causing health inequalities; such as marital status and employment status (p=0.001, p<0.001) (Marmot, 2010). Those with lower educational attainment had non-significant differences in service use (p=0.062), however this may be due to insufficient power amongst the primary school level group. They had a clinically significant difference, with double the number of visits or contacts compared to the other groups (18.5 vs 6&7). There were significantly more hospital admissions and sick days in the group with lower educational attainment (p=0.001, p=0.001). There was no difference in use of secondary care (p=0.624) and the same number of sources of information were used, however those with university level education were more likely to use non-NHS sources (p=0.001).

A lower level of educational attainment was associated with lower quality of life (p=0.005, p<0.001), despite fewer complications from diabetes (p=0.001). Only two (17%) people within the primary school attainment group were able to report their HbA1c result, compared to the university level group where everybody was familiar with HbA1c and 75% were able to report a result, with almost half achieving an HbA1c <7.5% (p<0.001). Additionally, more people in the lower attainment category used twice daily premix insulin, or a non-traditional regimen (p=0.032), although this was non-significant after adjustment.

Figure 11-10: Subset analysis of those not attending SE.
Bar chart of coded subcategory for barrier to attendance at SE according to educational attainment.

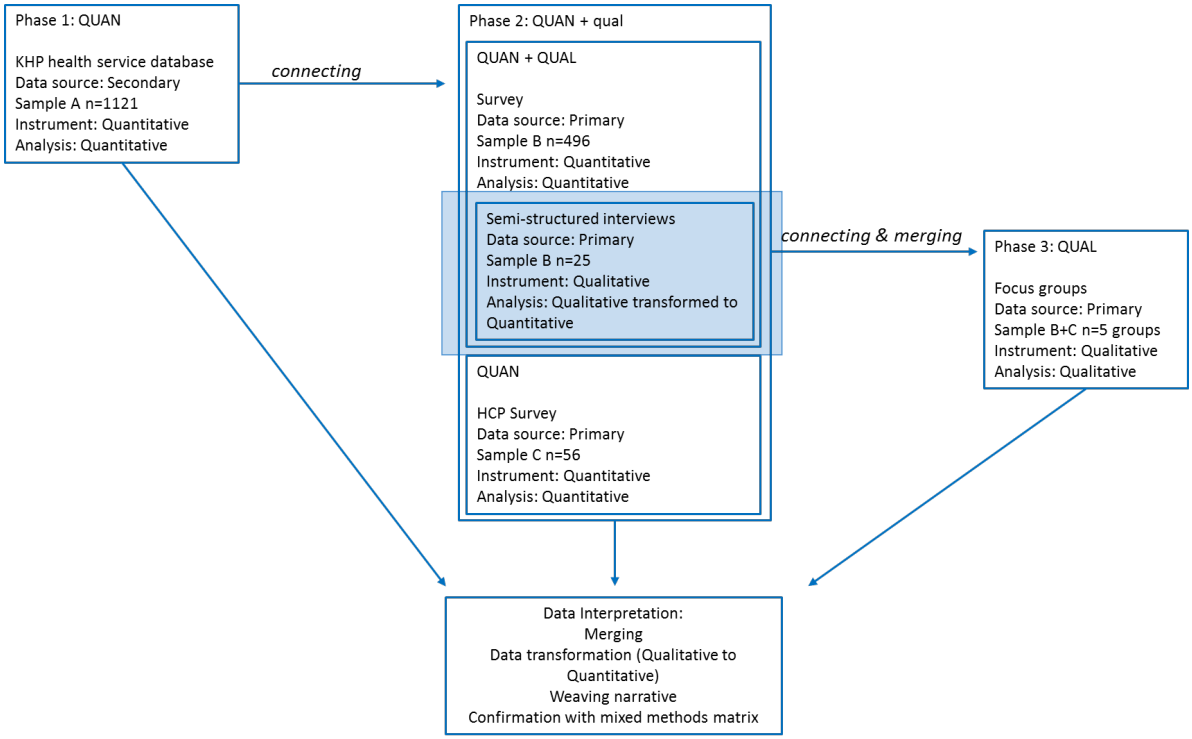


Although significance was not achieved after Bonferroni adjustment, Figure 11-10 highlights the different barriers for the three educational attainment groups. Those with lower levels of education reported time commitment or course requirements (including duration) as less of a barrier (commitment 25% vs 57% and 60% and course requirements 17% vs 15% and 12%), but tailored need was a large barrier (25% vs 0% and 2%) as was improved marketing or administration (17% vs 9% and 7%). The marketing group captures individuals who have not heard of SE. The perception of low benefit in the primary school group (17% vs 10% and 14%) may be because they do not believe they will learn or cope sufficiently with the course material, and therefore the amount of time spent on the course will reap little reward. Some of these possible explanations will be investigated further by the qualitative work.

11.11 Key points & Discussion

- Non-attenders:
  - Were male (p<0.001)
  - Were socially deprived; lower educational attainment (p<0.001), not in full time work (p = 0.002) and from BME groups (p = 0.008).
  - Had low health literacy (p<0.001), with fewer sources of information (p = 0.005) and limited knowledge of their diabetes (HbA1c) (p<0.001).
- Barriers to attendance at DAFNE were predominantly related to the attendee; time commitment and low perceived benefit being the commonest.
- Multivariate analysis identified four variables associated with attendance at DAFNE:
  - Female gender
  - University level education
  - HbA1c 7.5-9%
  - Positive HCP message about DAFNE
- One quarter of non-attenders had limited clinical need for DAFNE (based on HbA1c <7.5% and low risk of problematic hypoglycaemia.
- Educational attainment was highly correlated with numeracy; Almost half of non-attenders had not attended University. Those with lower educational attainment were socio-economically deprived, with greater unscheduled service use despite fewer complications related to diabetes and rarely quoted other time commitments as a barrier to attending DAFNE

12 Phase 2 Sample B: Semi-structured interviews



12.1 Methods

The recruitment method for Sample B and the qualitative methodology have been described previously (7.3.1.2). The coding of interview data and creation of the thematic framework for analysis will be described below, with the results.

12.2 Results

Twenty-seven interviews were carried out. Two were excluded by protocol, leaving twenty-five, as it transpired during the interview process that they were ineligible; one had type 2 diabetes (although she thought she had type 1) and the other was an asylum seeker.

12.2.1 Coding of the data

The coding of the qualitative research data was an iterative process, using the thematic framework guidelines set out by NatCen (Ritchie et al., 2013). The process of creating the framework for my data and the resultant themes are described below.

12.2.1.1 Data management

I conducted all interviews in person, using a structured topic guide (Appendix I). Interviews were transcribed and I read the transcripts once before analysing them in NVivo 11. I made notes of early themes that appeared to be arising along with reviewing the field notes I had made during the interview process. Some of these themes were influenced by existing evidence and Phase 1 work whilst others were inductive and led entirely by the data.

These early themes were used to label each case's transcript. This meant that each case had multiple extracts that represented fractured discourse and provided the evidence for further interpretation of the data.

12.2.1.3 *Abstraction and Interpretation*

These early themes were refined with further input from experienced qualitative researchers and service users. I then created a framework with which to code the entire dataset (see Table 12-1).

Table 12-1: Table showing the early codes emerging from the initial familiarisation with the transcripts, and the interpretation of this into evolving themes.
The different colours represent the groups assigned to create the overarching themes.

Initial Code	Emerging theme	Defining characteristics
Insulin use	Confidence with experimentation	Confidence in self
Experience of dose adjustment		
Experience of hypoglycaemia		
Experience of hyperglycaemia		
Strategies for hypoglycaemia		
Strategies for hyperglycaemia		
Errors in self-management		
Experimentation		
Carbohydrate counting skill		
Experience of diagnosis	Stigma and psychology	Psychological capability
Denial or psychological issues around diagnosis		
Emotions or beliefs associated with T1DM		
Checking blood sugar		
Stigma		
Locus of control	Personal responsibility for T1DM	Internal/external judgement
Burden of self-care or disease		
Effect on family and friends	Support networks	
Peers or support network		
Opinions of health service		
Pre-existing T1DM knowledge	Not relevant	
Finding advice or information	Knowledge finding	Self-education
Thirst for knowledge		
Use of technology		
Literacy or numeracy level	Barriers to SE	Numerical capability
Competitors for time		Other Barriers
HCP barriers		
Other barriers to SE		
Opinion/knowledge of DAFNE	Barrier/Enabler	Recoded to barriers/enablers
Previous experience of SE		
Benefit or motivation to self-care	Motivators/Enablers	Enablers
Benefit or motivation for SE		
Ideas to improve SE		

Each case was then summarised into Microsoft Excel, using both raw data and my interpretation. At this point I spent time reviewing the themes, looking at the over-arching themes and considering how they linked with each other in the light of my study and existing research. There appeared to be

some typologies emerging so I converted some of the key themes into numerical scores based on the data, which were colour code to aid visualisation. For example, numeracy was scored; unable to read numbers, unable to compute simple dose adjustment/corrections, unable to compute carbohydrate portions and consequent insulin dose, confident with dose adjustment, managing minutiae such as micro-bolusing or adjustment for exercise. This helped me visualise emerging types, confirming or rejecting any occurring typologies. These emerging types were further refined to identify key characteristics of each type or characteristics that defined a case as one type rather than another.

12.3 Themes and Types

There were six key themes identified in the qualitative analysis (Table 12-1); confidence in self, psychological capability, internal/external judgement, self-education, numerical capability and other barriers or enablers to attendance. Each case had different strength of presence of these themes. For example; knowledge finding ranged from present with people using multiple sources of information on a regular basis, to individuals trying to find information but being easily put off, to those not actively searching for themselves and relying on advice given by others, to individuals who actively avoided information about diabetes. Categorising individuals according to where they fit on the spectrum for each theme allowed recognition of four types (A to D). It is worth noting that interviews were only carried out with those who had either not attended DAFNE or were not on the waiting list to attend. Therefore, it is likely that an additional fifth group exists of people who are ready to attend, and have been referred but not yet attended.

There were two key elements that defined the types based on capability to self-manage according to acceptance of diagnosis and ability to perform the numerical procedures required. Type A and B both had the numerical skills required to manage FIIT, however type B felt external judgement and had problems prioritising attendance at SE. Type C did not possess the numerical skills required for FIIT. Some people (categorised as type D) were unable to accept their diagnosis, and this underlying psychological issue was the most fundamental barrier to self-management. Those categorised into type D also fit into another type, however their anger and denial of diabetes outdid other characteristics. Their denial and anger needed to be recognised and addressed prior to focusing on barriers associated with the characteristics of a secondary type (B or C).

Table 12-2 shows key demographic characteristics of interviewees, their study number and the type they fell into. Their study number will be used throughout this chapter to identify their quotes. Most (92%) individuals sat clearly within one type. Two participants (8%) fit predominantly into one type

but had features of another type. I have presented these outliers (1240 and 1796) data within both the groups that they fit into.

Table 12-2: Table of interview participants, showing demographic characteristics (gender, current age, ethnicity, age at diagnosis of T1DM and disease duration) and categorised 'type' according to qualitative analysis

Study number	Gender	Age (years)	Ethnicity	Age at diagnosis (years)	Duration of T1DM (years)	Type
1105	Male	27	White	25	2	A
1236	Male	31	White	26	5	A
2134	Male	28	White	21	7	A
2358	Male	41	White	24	17	A
6001	Male	30	White	29	1	A
1240	Male	31	White	4	27	A/B
1085	Female	26	White	3	23	B
1120	Female	27	White	14	13	B
1769	Male	63	Black	35	28	B
2359	Female	41	White	11	30	B
2634	Male	60	White	51	9	B
4031	Female	28	White	6	22	B
6003	Male	31	White	6	25	B
1505	Female	44	White	3	41	B
1114	Female	27	Black	17	10	C
1134	Male	27	Black	19	8	C
1374	Female	37	White	28	9	C
1798	Female	69	White	18	51	C
6002	Female	38	Black	20	18	C
1796	Female	68	Other	43	25	C/D
1527	Male	43	Black	30	13	D
1732	Male	58	White	4	54	D
2019	Male	20	Other	12	18	D
2059	Male	24	White	16	8	D
2504	Male	50	White	42	12	D

12.3.1 Type A:

Five (excluding the outlier) of the 25 interview participants fell into this group. The defining features for this type are outlined below with evidence taken from the semi-structured interviews.

All type A's were male, and aged 41-27 years old. One interviewee (1240) sat between type A and type B, he was the only one with a diagnosis made during childhood. The rest of them were diagnosed as adults, and two were in 'honeymoon' period. They were all Caucasian and had professional employment, having achieved at least University level qualification. They were **well-educated and numerate** and cognisant of their fortune at being so.

> *1105 "I'm literate, and I also have medics in my family and things like that, so I'm definitely starting from a better place than most people-,"*

1236 'I'm very, very lucky to be pretty well-educated"

2134 "I tend to have a very analytical mind, and take stuff in... in a detailed manner-, So [numeracy] not a problem-"

2358 "I've got quite a… scientific background as well, so that, sort of, seemed like a-, I guess I can cope, go through the logic of-, Trying to work out if it was risky or it was…worth the downside."

Each of them had **embraced their diagnosis** and fully integrated the behaviours associated with self-care into their lives. All of them were diagnosed as adults and some even discussed the positive effects that the diagnosis had had on their lives.

1105 "getting it in mid-twenties was pretty good…I could, sort of organise it into my life" and "it's not that bad...there are benefits to be had".

Every individual described the additional steps that they were prepared to go to achieve as close to normoglycaemia as possible.

1236 - "a lot of testing …an hour's exercise a day minimum to get the sugars down when they need it, a lot of mental and physical effort goes into controlling it."

They could vocalise at what cost this had come at and had strategies to integrate the behaviour modifications into their lives.

1105 "I can't, umm, err, eat a meal, get drunk, have sex, umm, run further than to the bus-stop, without seriously planning it."

6001 "I probably don't go out and have such a, boy's times on the weekend and limit that a little bit more…, and probably changed a few things where I, I don't know, maybe catch up with mates a bit more for a, just a drinking session at some point, kind of curb that a bit, and taken it up with other activities, such as being more, my photography, and a few other things that I do on the side, like hiking-,"

They showed an ability to make a calculated decision about the level of effort required and the consequential long-term effect.

1236 "Sort of trying to get somewhere in between, where you can live with having the odd hypo, had one last night, they're not very fun, but you're not running at a level that makes you think you're going to be at risk."

2358 "I don't know, I'm kind of half expecting, at some point, just to be completely burnt out and go, 'This is all too much, I need to sit and-, in the sun, and do something else… that's one of my concerns, is that because it is quite-, it's like everything I do, it's both my…personal and my-,… kind of business life is revolving around this that I'm slightly nervous that might happen at some point… but definitely paying attention to it more does result in better control."

These decisions appeared to be borne from a feeling of **personal responsibility** for their diabetes and not wishing to have any regrets about the level of effort they gave to diabetes management, even if at the cost of offending others.

1105 - "pride and bloody-mindedness and…determination to...get it under control"

1236 "I don't, you know, want to have someone remove a foot of mine at the age of 40, because I haven't looked after myself" and "it's kind of none of their business [injecting in public] ...I don't care what they think...it's my health"

2134 "I want to make sure I do everything I can to look after myself" and "my life is more important than someone's sensitivity"

2358 "So that's sort of depressing in a way [diagnosed neuropathy], but, so you get motivated, so, well, I have to do everything I can to try and-… kind of stay healthy."

2358 "I suppose if you go out, there's like a social, sort of, awkwardness thing, because you don't want to be the difficult person who has to order it off-menu, or-…Umm, I'm kind of over that now, so I don't, I don't mind doing it."

This feeling of ownership appeared to be in spite of often having collaborative relationships with healthcare professionals, and utilising the support offered by either diabetes peers or loved ones.

6001 "I think I've got to do things at my end to ensure that, umm, I'm managing the best I can. I'm the only one that can manage it on a day-to-day basis. I get input from doctors, but it's down to me-,"

1240 "… got my Excel spreadsheet, and, err, I send it across to my GP-, And he looks at it, and says, 'Yep, okay… but, you know, if there is a problem-, I'm, I'm the one that's raising that problem. And I'm coming, I'm coming to them just to double-check. It's more of a, more of a back-up…"

1105 "I'm kind of fortunate, because my boss has got Type 1 diabetes, so I've got complete carte-blanche (coughing) in terms of taking time off-."

1105 "it's not useful information [chats on forums], it's not something I can do anything with, but it's, it's simply a shared experience-, that is massively comforting"

2358 "but actually speaking to people, that's-, it's like, so I have kind of built up seventeen year's knowledge of how I, sort of, manage my diabetes-… And everyone's different, but, umm, it wasn't only until about a year or two ago that I ever met anyone else with Type 1 diabetes…And I kind of got in contact with people through Facebook … Umm, but since then, you know, everyone else has been struggling in the same way, and although not all of what they do is relevant to what I do-…Umm, a lot of it is, and I could have, you know, I wish I'd spoken to them fifteen years ago…it can be quite lonely sometimes-…so it's nice to have that sort of support."

6001 "I'm pretty lucky I've got, umm, a very good fiancé, to me, she, err, she does all the food buying in the house and she-, generally she's the one having to, err, make sure what she's bringing into the house is, umm-… appropriate for me to eat, so I'm, very lucky that she, certainly, goes above and beyond to, umm, make things as easy as possible"

6001 "I think I've got to do things at my end to ensure that, umm, I'm managing the best I can. I'm the only one that can manage it on a day-to-day basis. I get input from doctors, but it's down to me-,"

Whilst for others the lack of support from their diabetes professionals had encouraged their self-sufficiency.

1105 "they [DSNS] never pick up the phone. I mean, you're really lucky if you get them on the phone".

2134 "I just kind of…worked it out for myself...by the time you get to talk to a doctor, well it can take hours and it's an awful waste of time and public money, when I know that, from experience, or whatever [give some additional insulin to bring BG down] ...it's just applying common sense"

The type As were **self-assured and confident in their own ability** and would question if something did not make sense to them.

1240 "I would say very well-controlled, umm, confident with knowing my limits and my blood sugars, and-, What I need to eat, and what I need to inject."

1236 "I wouldn't leave the consultation feeling, 'Hang on, I don't understand-…that any more, sorry, I don't understand that enough, and I want more information before I leave'."

They showed a **thirst to understand** their condition and saw the benefit of knowledge; both the pathophysiology of diabetes but also the knowledge afforded by tracking and reflecting on day-to-day glycaemic control.

1105 "I'm just super-cautious" testing up to 10 times daily to assess "what it is that I need to do next, and how, how quickly I 'm changing" to achieve this "I want as many [glucose meters] in as many places as I can".

1236 "I am a prolific tester. I don't know how people do it without testing-,"

1240 "… I'm looking for, umm, certain periods of the day that I'm going a bit lower in sugar, or going a bit higher in sugar-, And then looking back at what I'm eating, and what I'm injecting, and why that's occurring..."

They filled any knowledge gaps left by their healthcare professional, with **self-study from various sources** from primary research to peer-led online forums.

1105 "I read the Diabetes UK newsletter every day-…, I bought, and people around me bought me tons of books, you know, the 'Dummies' Guide to Diabetes' (sic), and, and there's one massive, purple Bible one that-, a lot of people recommend-, I do occasionally look at the forums, I don't participate,"

1240 "… I suppose, since starting high school, umm, and moving away from the hospital doctor, umm, I felt there was a lot of support around there, umm, I then kind of self-managed my diabetes. Umm, and I haven't been on any training courses since, umm, or any updates. It's been all self-research…"

2134 "when you hear something in the news, I, you know, go to general media. If I want to find out something really detailed, I might look out for, rather, a research paper that's driven a news story." and "I treat general media with a pinch of salt-, …and tend to assume that if something's, sort of, on a Government-backed website, it's going to be reasonably reliable, and if it's in a peer-reviewed journal, it's going to be reasonably reliable."

2358 "I guess, when I was managing my diabetes up till a couple of years ago…. You did-, all sorts of things would happen, and you just didn't know the cause and effect. Umm, and without that knowledge, it's really hard to try and do anything about it." "[I] really struggled to get any sort of sensible information. If you-, yeah, it's just impossible…. Umm, so definitely not just out-and-out Googling. It's really just books, actually, before-, social media." But "It's interesting, umm, I guess so much of how I manage my diabetes is, sort of, self-taught or sourced from other people with diabetes-,"

6001 "it's part explained by the umm, doctors, and then I went away and filled in the gaps of the other bits and pieces I wanted to know, when I wanted to read-,… And had time to sit

down and, and take it on board, umm, I was-, yes, I got it from a few ranges of different sources, umm, some friends of mine had bought, err, diabetic cook books and things like that"

Having armed themselves with sufficient background knowledge they were then able to filter out the information that was of value to them.

1236 "So, you get a lot of people that kind of are trying to help, I mean, I work in the health service so I get a lot of (laughter) anyway, but you-, people who are trying to help, know a very little, and that doesn't help at all." and "I think that's quite difficult, because the number of people you can have a sensible conversation about Type 1 diabetes is small."

1236 "I don't, don't listen to GPs, don't listen to the diabetic nurses, don't listen to-, who else would I talk to?" so "really the only person that I have a truly sensible conversation with is Dr Z, because he's been there for three years, he's seen me from the start, and we've always had sensible conversations where, you know, he's made me feel he really knows what he's talking about."

1105 One particular DSN was "struggling with the formula" and "a lot of the conflicting information that you do get, and that's-, That's not the fault of, like, medics that, you know, that, that they believe different things or they've read different research or something, I don't know, umm, but it happens, and so, and so it's, it's really comforting to talk to someone who also, you know, gets that-, umm, and, and also, like the anomalies [of unexplained ups & downs]"

They could then make informed decisions about their diabetes management, with the **confidence to use experimentation** safely, and reflect upon the results to increase their understanding and further refine their self-management.

1105 - "a year ago, it would have occurred to me, 'Right, I need to call someone, and they can talk me through this, because I don't know what I'm doing', but, kind of a year down the line, I, I mostly feel like, the quickest and, umm, best source of, of help is probably just going to be, like, me, just like trying to work it out, and maybe, maybe do some Googling-";

1105 "experience teaches you after a while the adjustments that you need to make to your insulin"

1240 "… since then I suppose, it's been just through trial and error, and, and knowing my body..."

1236 "Trial and error, using my body as a scientific experiment for five years."

2134 New foods require trial and error and then reflection to "adjust my behaviour in future" and "I just commit it to memory".

6001 "I know, is kind of trial and error. I'll get there at some point, at, umm, finding what the solution is for myself. I've, I've read some of the athlete stuff, umm, which is, I don't know, it's reassuring… it's just trying to, at the moment, find the solution"

Through this refinement process they could strive for their fundamental goal of excellent glycaemic control, with a focus on the long-term future and complication avoidance. They appeared to be less averse to hypoglycaemia than other groups (see below).

1236 "I went into a GP once, and he said, 'You're in the range, that's great', and my sugars were 7. Well, what does that mean? Does that mean that I can expect a normal life? No, actually it doesn't. It means that my complications are, whatever, 3%-, As opposed to 98%. Umm, that would help me". But for him "as a well-controlled diabetic, I don't want to know about my next ten-year risk horizon, I want to know about my 30-year risk horizon-,"

2134 "if I have a blood sugar that's too high, and I end up being, you know, blind and limbless, that's going to be really, really crap. If my blood sugar level, in the unlikely event it became so low I were to die, well then I'm going to be dead, so I'm not really going to be-, (laughter), you know, inconvenienced by it-, Because I won't be aware of it. So I'd rather have it at the lower end of the scale than the higher end."

Their forward planning extended to considering potential hurdles and creating strategies to help them overcome them in the future.

1105 A colleague with T1DM is "kind of at a different stage…once my honeymoon dies down…I think I'll need to, kind of, tap that information slightly more"

The **barriers** to attendance at structured education for this group were broadly **low benefit** with an element of **missed opportunity** as they had reached a point of expertise through self-education. These barriers are discussed below.

The type As were concerned about the amount of time they would need to commit to the course for an unknown return on that investment.

1236 "having what I can perceive to be good control for Type 1, and a busy life, just makes the, the, the perception of having a-, four-day course, where you don't think you're going to get that much more benefit, not worth it." And "no-one's going to tell me anything on a course that I don't know-,"

1240 “I don't think I would get enough reward out of it to justify that five days-… I'm at a stage in my life where my time is very precious… [if] I was struggling. Then I would-, then I would think, 'Okay, yes, it's worth me putting my health first-,' 'Umm, ahead of my career or, you know, my family situation's going on very well, my, my personal time'...”

2358 “I think for me, umm, this is going to sound a bit, kind of mean, umm, but I didn't have that much faith that either the endocrinologist or the DSN-…was able to give advice that really, kind of, worked. Umm, and I didn't have any faith that spending a week, for them, sort of, telling us all, 'Do this, do this', would have any kind of beneficial-,”

For some, this perception of little benefit was also held by their healthcare professionals, who did not encourage their attendance.

2134 "She [DSN] thought 'Well, yeah, it might benefit you, but it seems like you're doing a lot of it already anyway'."

Whilst for others they had not attended because their healthcare professional had advised them against it, as they were in the ‘honeymoon’ period.

6001 “I wouldn't mind doing it. Umm, I've got, as I alluded to earlier, I, I like to learn as much as I can, umm, but I'm taking their advice at the moment, as that they don't see it as the right time just at this moment-,”

1105 can see the benefit in DAFNE as "it's meant to last you for the rest of your life, so I kind of figure...that does make sense" but has not yet been referred.

This strategy of waiting until honeymoon was over risked missing the opportunity. Most type As were keen to attend SE at some point, however the system had been unable to offer a course in a timely manner. Therefore, they self-educated in the interim, reaching a point of proficiency at which they could no longer see benefit from attendance.

1236 “I was down to do the DAFNE programme in X, when I was [studying]-, And they didn't have any spaces until after I'd left…So I've never picked it up since then…had it been offered-, had I-, could I have done it at X, I would have done it straight away.”

2134 “when I was initially diagnosed I was living in A… And, for whatever reason, they didn't have any courses available there at the time. Then I went to B to go to university-… and, umm, I think they told me at the time, yeah there were courses, but the waiting list was something like eighteen months-,”

1105 “I'm now keen to do it-, sometime in the next couple of months, and I've, umm-, I would, I would like, umm-, yeah, slightly more co-operation in, in booking that, basically.”

Due to the level of background knowledge that this group had, and to overcome the perceived lack of benefit, a course would need to be structured towards those striving for tight glycaemic control and the consequences of this.

> *1236 "Structured education course would have to, kind of, deal with the things that are your biggest problem at the moment, and most people's problem is, of course, just getting their sugars down, but actually when you're quite well-controlled, that doesn't tend to be the problem, the problem tends to be, okay, what are the symptoms of being well-controlled?".*

The type A characteristics define a group that are extremely capable and motivated. They are striving for tight glycaemic control, ultimately to satisfy themselves. They are self-confident and willing to experiment with their diabetes, using reflection to help hone their self-management strategies. I have named this group '*go-getters'*, as they have found information by themselves and for themselves; self-educating to the point of seeing little benefit from attendance at SE.

12.3.2 Type B:

Type B was the largest group, with eight participants (including one outlier). The type B's had the skills required to achieve FIIT. They were **numerate and educated**, all of them had professional jobs.

> *1085 "I did maths at A-level, so-, (laughter)… I like being educated (laughter), umm, so that wouldn't put me off [DAFNE]."*

> *2359 "I'm not brilliant with maths, but I can do the basic stuff around that"*

> *4031 "I like the science to be presented behind it… Because my background is slightly more-, it's biology, it's a bit more medical research, so my background probably means that I have a bit better basic knowledge about just the biological processes behind it-,"*

The **acknowledged their diagnosis**, although the level of acceptance appeared to be less than that of a 'go-getter', as they were unwilling to fully embrace it and allow it to impact on their daily life.

> *1085 "Umm, I think generally, I-, this is not probably a good thing, but I've never wanted to differentiate myself from any other, sort of, normal people without diabetes. So, umm, oh, I always-, it's not that I try and hide it because I'm embarrassed of it-, … But I try not to let it affect a lot-, and it's never really held me back from anything."*

> *4031 "it's just that thing of, I don't perceive myself as being in bad control. I don't-, I feel like I cope fine, so I don't feel the need for support… because diabetes to me, it's, it's just one thing that you do as part of your day, so as long as it's fine, then it doesn't need to be thought about more than that, so it's sort of-, yeah."*

Many had lived with diabetes for over half of their lives, with six of the eight being diagnosed as children. They managed their diabetes in a more lackadaisical way, often **relying on luck and gut instinct** than evidence (or blood glucose readings) to make decisions.

> *1085 "I try and do blood tests as much as possible, but it's often quite difficult to fit it in."* ***How many times do you think you actually get around to doing it?*** *"Oh, oh dear. Probably about twice a week, which is not enough, but because my-, and I know when I say this, it's probably not even the case, but I feel my-, my-, I know when I'm going a bit low, or I know when I'm a bit a high, and that-, yes, that's not an accurate, sort of-, description of how low or high I might be, but, umm, I'm quite, sort of-, my body knows that, and is used to that feeling, so I probably have become a bit, umm, apathetic with blood tests. But it's a constant thing that I know I have to do more of (laughter)."*

> *1085 "I know if I've got a big plate of potatoes on my plate, I'll need to some more insulin, so it's not a conscious thing for me-, I just adjust it, sort of automatically. And again, that's probably not very accurate-, and I'm aware of that, and keen to, sort of, be more accurate with that, but it generally seems to work."*

> *4031 "I think a lot of it is grounded in lots of experience, leading to sensible decisions. Umm, I don't carb-count or anything, I don't-, so guess a lot of doctors will probably say that all of it's trial and error, because I don't test as much as they should. I don't count what's going in and what's going out, I don't plan that well." and "Yeah. It [insulin dose] would change. Partly based on how I feel, so if I haven't done a test, it's on whether I'm feeling low or high, or-, so I still can feel quite well, whether I'm low or high."*

> *4031 "And I know that it's not the best measure, because actually you can be going up and down, and up and down, and it comes out as a good HbA1c, and I think-, I'm testing more now than I used to, and I think, I'm noticing that I am much more up and down than I'd like to be, but because it, sort of, ends up fine-, It-, to me, it's a lot of extra effort for something that sort of ends up okay… My style of diabetes management has always just been lucky, I think"*

> *6003 "The less I think about it, the more straightforward it becomes."*

Despite the ability to manage their diabetes without much effort, they were mindful of the fact that they should be paying more attention to it.

> *1085 "I feel like it's part of me, and I, sort of, can control it-, without even, sort of, thinking too much. I always know there's room for improvement, and room to be stricter, and room to-, you know, I'm very aware that I could be better at managing it. And I guess that's why I've always been quite keen to, sort of, learn a bit more, or have a closer relationship with my hospital, or even people that have got it, so that I can, sort of, absorb some knowledge-,"*

1240 "…you don't fix something, or try and fix something that's not broke, I mean- I think, because I've been quite well controlled, so far-, I've just felt it's fine, just to, just to carry on with what I'm doing. I suppose it's almost like resting on your laurels a little bit…"

They talked about **wanting to improve** their diabetes management and were aware that their current practice was not exemplary, often pin-pointing the areas that needed to be improved upon.

1120 "And do you think how you're managing your diabetes at the moment is, you know, the best it could be? No. What would make it better? Umm, I think, to be honest, choices, so for example, I would drink in excess at weekends, not every weekend but, you know, on a fairly regular basis, particularly during summer time with hen-dos and weddings-, And I think that part of my management, umm, and also, probably having less snacks that I don't do my insulin with, would also help, umm. And I guess, just making more of a conscious effort of, you know, checking and-, Making sure I'm kind of more consistent, so it's a choice rather than-, it's a choice at that point in time. And I think it, it could be much better, and I would know how to make it better. Umm, it's just a-, yeah, choice at those times.

1085 "But I also know that there's a lot of stuff that I should do that I don't, and I want to, sort of improve on that. So that, that's the non-confident part of me-,"

1240 ". Umm, so I tend to do blood sugars now, but I can tell what my blood sugars by about 0.2 or 0.3 out… And I think I could be, as I said before, more proactive in areas."

2359 "Like I think I'm guessing [insulin dose], and I still have a tendency to over-guess for some reason, so then, in the evenings particularly, I get really irritated with myself… I'm quite a manic person, I'm always juggling ten balls in the air at once, so I, I will tend, so still go, 'Oh, that's probably about twenty [units]', rather than really go, 'Is that really about twenty [units]?' or, if I really add all, all that up, and thought about how that all panned out-, Would it really be more like ten [units]? And that's where I fall down. "

2359 "And now I've got more access to information-, And I could be better, the thing is I could be better, because I could, as you say, like, access more information-, And I could also spend a bit more time thinking more carefully about my hypos, and planning it-, But I-, yeah. But I don't, yes, I don't get it right all the time"

6003 "I'm not a pro at it, umm, but, you know, I think that's, that's how it's panned out, now."

1505 "I'm not sure I would be the ideal role model for people to learn off, so (laughter)."

The need for improvement was driven less by a personal desire, but more by a feeling that those around them might think it was necessary.

4031 "So yeah, I do, I do put it up and down, but it's more, sort of, on-, it's just probably not as systematic as-, people would like it to be."

4031 "I don't think you guys would want them learning from me (laughter). Umm, maybe? I, I'm not in-, I'm not that inclined to give people diabetes advice, because I know that I don't do it the way it's meant to be done, so I personally don't think people should learn from me about their diabetes control, because I don't think I'm the best example"

6003 "And I think, 'You know what? My wife won't appreciate me without any legs' (laughter). And, and I go and measure my blood"

They demonstrated some background diabetes knowledge, but not to the same extent as the 'go-getters'. They **rarely reflected** on their previous practice in order to make changes to their strategies, often relying on formulaic tactics and chance.

1769 "once I start going into double figures, I start get worried (laughter)…Err, sort of, err, inject a little bit of insulin-, To bring it down. That's what I do."

1120 – "I kind of carbohydrate-count… Umm, so I've, kind of, taught myself that-, just from, kind of, part education, part-, umm I guess winging it (laughter), umm so I think that's probably helped significantly, because it's only been in the last couple of years that I've really been doing that-,"

2634 "I know to, how to do all the things, but there's always the improbables, like the hypos."

4031 "I guess, maybe this is why I don't like carb-counting, because, sort of, by accident, I've just, sort of, got it right, so I feel really good about it (laughter), so it may be part of that, yeah. ***Kind of pot-luck thing.*** *Yeah, and you're like, 'Oh, well done me. I guessed that and it was right'. And you're like, 'Oh, didn't I do well today'."*

6003 "Drawing lines on graphs, and then-, so, but yeah, I guess-, yeah, you-, you've only actually made me aware of that, quite how, how the technology is actually, sort of, disconnected me from that, that reflection."

They lacked the confidence to ask for help when they did not understand something or needed assistance.

2634 "And I didn't tell anybody. I just came off it [metformin] because I thought, 'I can't feel like this, I've got long work days, I've got stuff to do, I need to be together to work, and I'll just keep going'."

2634 "Well, every morning, when I take my first reading, and I go, 'Oh, oh dear'. I go, 'I really should talk about the Lantus to somebody'. But then the day goes. Do you see what I mean? I mean, I-, because I don't-, I don't obsess about it."

2359 "do have problems with maths for the exercise, I find that really, really hard, and I still don't really get it right. And I still don't really understand about food. But this, I found that, I did find the, the exercises so complicated, that I didn't find it out, so I still find that quite difficult."

6003 "Umm, just a kind of, 'Well, we need to see you about-, we need to talk about your new medication', and I thought, 'Excuse me, what, what is there to talk about? I'm on it, here, here are the packets', umm but yeah, I mean, even it-, like irritating stuff like that, I just kind of, you know, I just sit through it and, I, I've given up struggling, that it's for my detriment rather than my benefit."

Their diabetes was not their number one **priority**.

2634 "I thought, I'll get, I would somehow get through this, but there were too many other things happening at the same time."

1085 "I probably need to make more of an effort to, sort of, take the time to do blood tests in public, and things like that, and I know I need to work on that, and probably (laughter), let it affect my life a bit more."

4031 "But it's just that initial step of making the effort to sit down one day and go, 'Okay, I have a sandwich for lunch most days, what's a sandwich [grams of carbohydrate]?'"

1505 "I don't want to go somewhere and have everything pre-set before I walk in. To me, that's not going out, that's not having a life-, That's being dictated to by a set of rules, so. I think you have to have some life involved in it somewhere-, It's sort of-, I'm not one to sit there with a book and tick crosses out, and do stuff mind every single day of the week, so."

They had less thirst for knowledge than the 'go-getters', **rarely actively seeking information** for themselves.

4031 "She [friend with T1] tells me about stuff that I've never heard of before, so I can go and look it up. And it's just nice to hear-, yeah. It's just-, yeah, it's useful just to hear about other things going on. Because I don't actively search for stuff about diabetes… yeah, I'm not really at the forefront of any of it, so she is, so it's really helpful-, to get that information, because I don't get-, I don't try and access that information any other way."

1085 "I can't remember doing anything like that, sort of searching for specific information. I don't think I have."

1240 “everything's social media and-, Err, documents are shared, and, you know, the, the communities can be created. I don't really feel there's that out there-, Within, within, you know, the diabetes community… I presume there's things out there. But I'm just not necessarily using it.

2359 " I don’t want to trawl through stuff, so in terms of accessing information, it's-, I, I don't really access information… I don't do any social media stuff. ***What about face-to-face stuff?*** *Like?* ***Going to diabetes groups, or pump-user groups, or anything like that?*** *I wouldn't even know to access them. I would have gone to a pump-user group, if the hospital had offered me one."*

2634 "It began to get complicated-, Because I didn't understand the ratio of carbohydrates to insulin-, For whatever reason." But "I haven't found the need to go looking for other stuff. I don't, I don't look up my own illnesses."

1505 “I don't really go hunting for it [information], I mean, sort of-, it, it would be more from a point of view if something came to my attention… I would, I would go and look at the papers rather than-, Listen to some story… but-, (laughter) sometimes when things are on the news or something-,”

They would often find information only when necessitated.

1769 “You, you know, so I went on the internet to do more of, err, err research, or not research, more of-, to get more information… And that was where I came across umm, umm, a website that actually sells, umm, a, a, band-, A rubber band. It's called, umm, Stay Erect. That's what it's called. So once you put it on, you, you, you know, you stay really erect-, You really f-, you get the, erec- erection straight away. You know, so that's what I use-,”

1505 “I think there comes a point where you have too much information… I think a lot of people don't have a clue what it means… I think it's dangerous to have too much information. I think it's better to, to stick to what you need…”

They felt it was someone else’s responsibility to give them the information required or at least help them digest it.

1085 “Err, yes, no-one's ever told me about these things [diabetes technology], so I'm clueless (laughter). ***Yeah, and so how do you think you could find that information?*** *I would assume from doctors and diabetic reviews, but they don't ever seem to really chat much (laughter).”*

1769 “And that's it, which of course, I think, as, err, then, I, I don't have much knowledge of it, which I think, err, I should be more, more informed about it. But I wasn't. Because I need to check my blood sugar every time, and I wasn't given that information, not until I came to this country.”

2359 "…so I am a self-teacher, but I'm not a very good self-teacher, because I find it quite difficult just to, kind of, go on and read stuff and then do it. Like I kind of need to have it talked to me, and then me go, 'Oh, but my circumstances is this', and someone say, 'Blah, blah, blah, blah'. And then I can do it properly. But if I'm-, but it takes me quite-, because I don't feel automatically confident that I'm doing it right-,"

1505 "I've already had the information about the course. I want to, just-, 'Give me a book, I can read it, tell me what to do',"

They were often **easily put off** or reliant on a small number of sources

1120 "Umm, I did download the Diabetes UK app, but it just-, it was quite a lot of work, like just-, it's okay if you sit down and do it at the end of the day, that's great, but if you're doing it all there and then-, It's-, the feasibility of completing that-,"

2359 "Because a lot of the books you got as well, when you were first diagnosed, they were kind of really crappy, written by Dr Doo-, Doolittle from Sheffield University, and it was like, wordy, wordy, wordy, wordy. So like they weren't, they weren't very accessible..."

4031 "So, partly online, umm, so Googling it, but not that helpful. There's lots of forums that are not particularly useful, I think. Umm, yeah, so either online, but I've never really had that much help, and then-… I guess the problem is it's always something quite individual, and they're [websites] very bad at giving you extra detail. And I guess, the forums where it's something quite specific, they're all, kind of, crazy theories that you don't-, they're just ridiculous-, So, I think there's not a lot of useful stuff in between."

1120 "Diabetes UK-, is probably generally where I'd go, if I need to just look something up-, or NHS Choices sometimes… Yeah, I trust them. I wouldn't trust many other locations (laughter)."

1769 "Yeah, yeah, very good advice, yeah. And that's, I'm sticking to that advice, it's-, ***Yeah. So he [friend with medical background (not diabetes)] advised you that you can take a little bit extra of the insulin?*** *Err, he didn't say that, he just said, err, if my blood sugar goes, err, above 10, 15-, I should be worried."*

*2634 "****What would give you the confidence to be able to do that [dose adjusting]? Do you think it's something you should do, or not?*** *I haven't a clue. Seriously, I don't know how to answer that question, because, err-, because I've spoken with people about the d-, the insulin. Umm, I trust what they've told me to do. They, you know, it's 5 to 1, 5 carbs to 1-, Thingy-, So I go by that-, Because that's what's been told to me, by people who are professional."*

1085 "So if you, when you have tried to look [for peer support] where, where have you tried looking, and when do you try? Umm, I probably, just online, just looking round. And there,

are there sites that you use online to find out information about your diabetes? No. No? No. So there's nothing in particular that you trust, or-, no. No. Do you go to Diabetes UK or anything like that? I don't-, I don't really know what resources they would offer, to be honest. I have been on their website, and probably looked around, a bit, but I just, sort of, associate them with fundraising, to be honest-, which is great, and I'm a member… but I, I, don't sort of actively-. Yes, are there any other names, or sites, or things that you-, No, no. And what about, umm, have you looked on-, have you looked at blogs, or tweets, or Facebook, or-, Umm, I think I did, a couple of years ago, look at Facebook, but no-, I don't (laughter), is the answer."

6003 "I generally trust Web MD and NHS Choices-, because I, you know-, you just know that they're written by professionals."

Many of them had a **background understanding** of their condition which enabled them to make a judgement about the amount of effort they put into managing their diabetes, and had considered the associated risk.

1120 "I'll quickly pop out to go to the toilet [to inject], and come back, so stuff like that would impact my control, because I-, it-, I'm not being as accurate, but I'm making a conscious choice-, to be less accurate, based on time or location."

1796 "But because I don't inject during the midday-, or before lunch-, that's why, you know, my blood sugar, you know, goes up in the evening."

1769 "I been, err, told from, from the beginning, at the, at the, err, the diagnosis-, that if there is, err, my sugar level goes above 10, 15-, then it will start destroying some, some, some of my organs in the body, slowly-, without me knowing. So there would be no pain, there would be no nothing, but slowly actually destroying me-, Then I'm very worried about that-, So that's why I keep an eye, I'm watching like a hawk-, to keep an eye on this (laughter). ***Okay. And so are you ever tempted to check your blood sugars through the day at all?*** *Through the day, no, because I, I work in, umm… So it's really pretty difficult for me to, sort of, err, check my blood sugar, you know, during the work-, work-, working hours.*

2634 "it wouldn't be nice to lose a limb, Umm, so I have to, to the best of my ability, do the right thing for my body. And, when I sit down and eat the tub of ice cream, I know it's not the proper thing to do, but, hey, do you know what, the alcohol nearly killed me anyway, so we don't do that now, and we just have to try to deal with doing that."

They often had strategies to reduce the potential harm done by their choice not to prioritise their diabetes,

1120 "Umm, social life-wise, it doesn't really impact it that much, it probably should impact it more from an alcohol perspective than I allow it to-, But I think that's kind of a conscious-,

I'm aware of the impact it has on my sugar levels, you know, I shouldn't be doing it, but I think I would-, I still continue to do that-," [but had found a strategy to lessen the impact] *"I guess through, kind of, experimentation really, so, umm, kind of, I've learnt which alcoholic drinks push my sugars up significantly, and I've learnt which alcoholic drinks, if I just stick to them, I would then have a hypo, so I kind of combine the non-sugary ones with some, kind of-, some-, so I have wine and gin and, kind of, slimline tonic, and balance between the two, so that it has less of an impact-,"*

2359 "Maybe I do need to do a bit more about what this post-breakfast dip, because that's also meaning I'm trumping through a lot of sugar, which I really don't like doing. So, but-, it's just difficult when you've got so much going on, life's pretty hectic. And so, sometimes, it's just hard to kind of-, because to, to do something about it, I need to really think about it, to test it, try it-, try out different things, and that, I haven't got around to doing that yet. But I will get around to doing it."

And the majority had reasons or excuses as to why they did not prioritise diabetes.

1769 "I work in, umm, a very messy, err, err, profession, because, err, when I operate on a patient, there's blood everywhere-, And I don't sort of contaminate myself-, And I, so I stay away from that, from giving myself injections, or-, anything, err, invasive to myself. You know, so that's why I don't take, err, injections in the, in the afternoon."

2634 "I have taken on board that I am a diabetic, right? As I have taken on board that I am an alcoholic. Right? And I get up in the morning, and my decision is to get through the day. Right? And I do."

4031 "Err, hungry, so you can't really be bothered [to check BG] (laughter). Umm, so my-, this is really stupid, but in my bag, it's quite hard for me to find [glucose meter] in there sometimes, so, like, rummaging around in your bag's a bit of a faff. Umm, if you're out and about, it's just difficult, sometimes, when you're out-,"

1796 "I'm getting old, you know (laughter). I'm not young. So I said, you know what I mean, you know, 'I'm-, sometimes', you know, I said… 'You might be around today, you know and then the next thing, you know, so'. That is like my, my priority? At the moment, you know, that I just want to enjoy life, that's it. And the diabetes… that my life doesn't revolve around my diabetes, you know."

Many were reluctant to share the burden of living with diabetes. They often did not inject or test in public, or in front of loved ones.

1120 "I think my partner does [understand], because they-, he kind of sees day-to-day the impact, but probably not even then, umm-, probably not, but mainly because I don't really talk about it with any, anyone particularly, you know, yeah-, I thought-, potentially. I don't know if I've ever really discussed it (laughter)."

6003 "it was-, and that was the first time [after 22yr] I'd actually spoken about how I felt about my condition-,

2634 "I am self-sufficient. I have no interest in other people's hypos, and I don't care if people are interested in mine."

4031 "I don't really like people getting involved. I don't know, I'm quite protective about it (laughter) …Because I've always been very independent with diabetes, I don't really like people knowing. It's really weird, I don't know why."

Some of them talked about being judged by those around them, either previous healthcare professionals or parents.

1085 "I probably got a bee in my bonnet from-, I had a really bad, sort of, doctor when I was younger, who just told me off for everything, and it's affected my-, you know, I'm embarrassed now, when I-, I hate showing people my blood sugar results-…just because I feel like I'm going to get told off."

2359 "I came from a family you just dealt with-, you just had to get on with it. Deal with it, get on with it, so, I mean, that's just-, and then you had those, sort of, doctors, so I thought, 'Oh well, like I've just got to deal with it, get on with it'."

4031 "I don't even like people knowing what my blood sugar is. A lot of the time I'll, like, hide it when I do it, it's very-, it's really weird" but "it [injecting] does quite often spark people to ask you about it, like people who genuinely seem quite interested. And so I kind of like that, because I don't-, I think it's good for everyone around you to know that you're diabetic.". Maybe it's "because these are, like random people. They're not like your mum, who's going to be, like, 'Oh, well, you shouldn't have that for breakfast'. Umm, they're random people, I don't mind"

6003 "It was an interesting experience being under the care of a kind of a very austere German doctor, who would, sort of, look at my blood charts, and we-, I had to-, we had to actually chart the blood sugar on, like, on graphs. Umm, and he'd-, sort of, if it, we-, it had gone too high, and he would just look at me, 'Have you been eating sweets again?'

1769 "I wouldn't do it [inject] at work, but I would do it anywhere. I, it normally would be everywhere, but not, not at work… [People at work] might be thinking, oh, I'm diabetic. 'I didn't know he's diabetic'. You know, a lot of talks, you know how people talk?… I think it's something personal and, umm, I shouldn't be telling every, everybody that, 'Oh, I'm diabetic, I'm diabetic'. I think it's private, that's what I think (laughter)."

1796 "And I don't want people knowing then that I'm diabetic. Because somebody will say, 'Oh, you cannot eat this'…"

1505 "I always get the feeling when I go to clinics, and various other places. People don't actually listen to you; they just talk down to you continually."

The main **barriers** to attendance at SE for type Bs lay within the relative lack of **priority** that was given to their condition, and therefore the amount of **time and effort** required to attend. Many of the reasons given for non-attendance were superficially associated with time and work commitments, but there appeared to be more complex underlying reasons that emerged through the interviews. These are discussed below.

Many type Bs quoted the time commitment as a barrier.

1769 "Five days, err, the problem with five, because I, I work, that's the problem. Yeah. I work, like, full-time… I'm self-employed… I would lose a lot of money-, And I need to pay my bills (laughter)."

2359 "I think-, I mean, if he mentioned a couple of times, but I can't really ever remember one, anyone, sort of saying that I should definitely do one. Umm, and the other problem is that they've always been such a huge amount of time. And, and for me, that's quite difficult, because I'm quite work-focused-,"

6003 "I mean, the reason I originally couldn't take it up was because it-, I think it was a three or four day-, course in the middle of the day. You know, that-, I don't know who came up with that, (laughter), that being an idea for the working population… When I don't work, there's no money."

1505 "I think probably, umm, a, a day, I, I could endure a day but-, (laughter). Five days, it just doesn't do it for me, so."

1796 "If I'm not doing anything, you know, and, umm, you know what I mean, if I'm not busy, I wouldn't mind, you know, and I'd go [to DAFNE]."

They found it difficult to equate what little they knew of the course content to five days' worth of material. They were doubtful that they would gain enough from the time invested in attending.

1085 "I don't want to spend my holiday (laughter) learning about diabetes when I don't know how much I would actually learn, because I don't really, couldn't really find out how-, what level of education you'd get-,"

1120 "the team [at work] are all very supportive. It just seems like a long time to take out of work for something that I don't really know how much I would gain from it, so, yeah. I feel like there may be days that I'd be really bored, and not really learn anything-,"

This perceived low benefit was related to the feeling that the marketing of the course was misleading, and many commented on the inability to find adequate information about what was involved.

1085 "I am normal-, I'm a normal eater, I would say, so-, 'Dose Adjustment For Normal Eating'. It sounds like it shouldn't take five days, to be honest, if that's what, what we are learning about. That would probably be a two-hour workshop, in my mind."

6003 "And that's how it's marketed at the moment; you're saying, 'Have you thought about doing a carb-counting course?' 'Yeah, I've been doing that for twenty years, like, don't reinvent the wheel'."

1505 "…we weren't told as to what it actually-, the structure of it was-, so maybe if that information was more readily available, then at least that you can see how it's broken down, what the sections are, what you're actually-, just a synopsis of each one…"

2634 "Because I see the DAFNE thing up the wall. 'What the bleeding hell is DAFNE? DAFNE?' when I first saw it. I hadn't a clue what it was. Now, I was only going to the clinic for the first time, but actually, I should have known what it was. I should have gone up to that thing and gone, 'DAFNE? Ah, yeah'. But it wasn't very clear."

1120 "I think there probably was a mention of carbohydrate counting, but nothing else, really, so my perception was then, 'Oh well, I can do that myself-,' in a ten-minute consultation, there's probably not very much time to talk about it, but I haven't ever been given any written information, or anything like that on that. ***Yeah. What do you think would be one of the compelling things that would make you want to go?*** *Umm, I don't know, to be honest. I think knowing exactly what it consisted of, so over those four days, what would you actually be doing-,"*

Some people were unsure as to where they should get more information about DAFNE, and felt that time constrained them from starting the conversation with their Diabetes Specialist.

2634 "Will I learn the tools of coping with the erratic? Did you see what I mean? I don't know what the benefits would be, because nobody's told me- …If the doctor brought it up, then the doctor would have to start to explain it, and that would elongate the length of the session."

Or that the clinical relationship lacked the depth and stability to enable them to ask more about it.

1085 "Umm, it's moved around, because I've moved around. The last practice I was with, it was A Practice, I think, I had a sort of reviews there and then I moved to the hospital now, but to be honest, it changes so much, that I sort of lose track of-, who I'm seeing, where I'm going, and when my last appointment was."

1120 "I've seen various different consultants. It was never really gone into detail of what it actually consisted of. I don't know if that's because it was assumed that I knew, because I did kind of know what it-. But yeah, not really kind of discussed in great detail of the benefits, or-, anything like that."

Whilst, two type Bs had received encouraging promotion of DAFNE, they were unable to believe the hype was true!

4031 "My friend and then all the doctors, everyone seems to think that's it's amazing. But what's put me off is it's five days. That's really, really long, and that's five days of annual leave to go and talk about diabetes (laughter). I know everyone says it's meant to be great. I've heard that afterwards your diabetes is meant to just feel, amazing, and you feel in control, and-, all the sugars, sort of, become flat and wonderful, but-, ***Do you believe that?*** *Mmm, somewhat, but I don't-, I do believe that the evidence is there that people that have done it tend to have low HbA1cs, or better control, more stable sugars. I don't doubt that that's true, but I doubt that it solves everything (laughter)."*

1505 "And everything was brilliant, and they weren't living life until they had-, came on this course, and to me… it sounded-, well it sounded a bit false to start with (laughter)"

Despite many of the type Bs quoting time commitments preventing them from attending, at least four of the eight had been given permission from work to attend. Despite this they chose not to, as they felt unable to set aside a week to concentrate on their diabetes. There may have been an underlying element of not wanting to be seen to receive special treatment at work, or to be different from others.

1120 "I didn't do it [DAFNE] purely because of work. My manager said I could have it off, but the thought of having nearly a week off-, because I think it's four days, or I think they said you can do some that's just half a day or a day, four times, or something like that. It just seemed like a lot of time to take off work, and-, I'm a bit of a workaholic, so I didn't really like the idea of that… I think that you are then leaving it to other people to cover your workload, and I don't really like doing that, unless you have to."

4031 "I'm sure [work] would be quite sympathetic, umm-, it's not necessarily the employer side. I mean, I'm sure most employers would feel pretty-, I'm sure most will let you have it, for fear of discrimination or something like that, umm-, but it's more you taking the time out of work, that's not-, but taking time out of work's quite difficult, like things are quite busy, you've got so many things going on, that you already feel, kind of, bad taking your holiday, and, like, switching off for that long. So I think if I was doing it, I would feel-, first of all, I would still carry on working, and I would just do it in my evenings-,"

2634 "Well, they told me what happens, they gave me the sheet, I looked at the schedule, and I thought, 'I can't do this'. It was because it was, like, on a Monday, Tuesday, Wednesday, Thursday, Friday, and I'm going, 'I really can't be out of the office', although my boss would let me… No, because I feel I have-, my work-, I-, my job is different all the time, and it's always ongoing, and like, I mean I've left the office tonight, but there are things hanging over me."

*1505 "So I don't think it would be an issue in getting the time off, but… I mean, obviously, if you need time off for something, you ca*n *get time off-, but I mean, I think it would be a bit inconsiderate to-, because it just means that somebody else has to take on your work-,"*

This sense of being different from others, or perhaps not wishing to bring diabetes to the fore and force daily recognition of it, caused one individual to not want to carbohydrate count.

4031 "I do think that-, more recently, I've been thinking that it would be, that maybe I should do the carb-counting thing, but I just, oh-, I know it's not, but it would just always feel like I was on some sort of diet or something."

A fear of judgement by others was recognised by two individuals.

1085 "I think if everyone was recently diagnosed, I'd feel like a bit of an idiot, to be honest, umm, or if every-, if there was no-one, sort of, similar to me, and-, I wouldn't want to go there and be the only one who'd had diabetes for 23 years, and should know better, type thing-, I wouldn't want to be embarrassed because of that …I just think that I wouldn't want to be the only, sort of-, sort of black sheep amongst lots of white sheep (laughter)."

1505 "I mean, I'm not against the idea of it. I, I just don't like the way that it's, it's done… I don't want somebody standing there, lecturing me, and telling me how to live my life."

But may have been present in many type Bs, as another touched on the idea of questioning the need for education after so long with diabetes.

2359 "You just chug along, don't you? And then, then by, by chugging along, that's not a good-, educating someone who's been chugging along for 30 years, or even, perhaps considering seriously that they might need educating."

Most had lived with their diabetes for a long time so had prior experience of some form of group education. This previous experience provided a backdrop upon which to make judgements about DAFNE.

2359 "Maybe, ten, fifteen minutes of it was something that I found useful, because the rest of the time was, kind of, going over the basic points. Or if someone was struggling to understand a point-, And I was, kind of, there and-, Ready to move on."

2634 "I've tried AA, it didn't actually work for me, because I couldn't-, and this is something that I also thought about DAFNE, because I know it's groups."

For the majority, this was related to being in group education and the requirement to go over material at the pace of the slowest learner, often repeating content that they felt they already knew.

4031 "I would find that incredibly irritating, and I just wouldn't want to be there, for stuff that you already know, so I guess the only thing that worry me about a group is that it has to be tailored for everybody who's there… So that-, because, I guess if you are going to go for the five days, you really want to make sure that every single question that you have, and every scenario that affects you and your life, you're going to get answered, because it would be really annoying to go for five days, and actually not have the things that you needed to know for your lifestyle-,"

2359 "Kind of, because I'm also-, everyone's got different learning styles, and I'm a really busy, pressured person at work. I, I juggle fifteen balls at once. If I'm going to give my time up, I kind of need it to be focused on how I learn."

1505 "I don't mean to go round and say that I think I'm better than everybody else-, I don't, but I think, probably, on an education level, I probably am."

To encourage attendance at structured education for a type B would require recognition of the fact that despite the longevity of their diagnosis the status-quo of current practice is not sufficient, and that it is acceptable to ask for help and acknowledge the need for further education.

1085 "I like learning, and I like absorbing knowledge and stuff, so I think that would probably be more appealing in a way for me-, Because I know that I would be taught something, and take something from it."

4031 "I guess more, umm, more awareness that-, I've had a few situations where I've been quite low, and recognised it, and dealt with it, but it was sort of a bit-, it was more low than I would like to have been."

6003 "Let's go back to the start, and let's just-, relearn it, also, you know, just to get affirmation that, 'Actually, you know, I'm doing it-, I'm doing it right'."

They need to be able to prioritise their diabetes over all else, as they are coping with the day-to-day management, but not mastering it. Strategies to motivate them to stop current behaviours and

make changes may include motivational interviewing which would need to be done within the foundation of a strong, non-judgemental and trusting clinical relationship. Opportunities to educate need to be grasped, particularly using new situations such as pregnancy or exercise, so the 'not-yetters' do not feel embarrassed for lack of prior knowledge.

1120 "So if my sugars go high I feel horrific, if they're-, if I'm having a hypo, I feel horrific, so having them roughly within… a range that I would feel well at, was kind of-, when I was younger… my-, goals, and motivator, whereas I think now… in the near future, looking at having children-, which, kind of the risks with pregnancy-, Umm, kind of, that's probably partly a motivator, and then being aware of the complications and, and not wanting to have those complications at a young age is… I think that's a huge motivator for me."

1769 "I think I will go for the, err, for the health, health aspects of it-, That, you know, at the end of the day, err, it's my benefit-, And, err, I'm going to improve my, myself, improve, probably, my organs in my body, so I think I'll go for it."

4031 "I guess as you grow up, you become, as you get older-, I sound like I'm really old right now (laughter), as you get older, I think, for me, you just become more aware of-, first of all, just taking care of yourself a bit better, umm. Again, I think just exercising, I didn't, I don't really like exercise much, but I'm starting to try and do it regularly-, Because you're just more conscious that it's good for you. Umm, try and cut down your drinking, because that's good for you. Take better control of your diabetes, because it's good for you. I think it's just part of, overall, trying to be healthier."

1505 "I always get the feeling when I go to clinics, and various other places. People don't actually listen to you, they just talk down to you continually. And I don't feel it's on a one-to-one basis, I just always feel that-, 'This is how you will do things'."

Many type Bs were unable to guage the usefulness of DAFNE due to insufficient information. Improved marketing of DAFNE would overcome this and use of peers may be a strategy but would require thought to overcome the current lack of peer support/relationships within this group.

1085 "I could be really savvy, and I could not be, I just don't know, because I don't have any point of reference-, Or anyone who's, you know, I have the occasional doctor that I see, and that's it."

1505 "…when you sit in a clinic, there's probably two people there with Type 1 diabetes, and the rest are all Type 2 diabetes, because they jumble everybody up together-, So it's like-, so the chances of you sitting, having a general conversation with somebody next to you..."

Alternatively using friends and family to encourage attendance may be of value, as this could be framed as providing education for a partner whilst giving permission to the person with diabetes to attend or alternatively using them to coerce attendance.

> *4031 "Partner, probably-, my partner's-, pushes me a bit to be healthier, and he asks me about it more. So I think having him there probably makes the biggest difference." And "I know there's a few diabetes Twitter people that I think my partner now follows, so he knows what's going on."*

> *6003 'Why would my wife want me to be irresponsible? I mean, she wouldn't want me going out partying and drinking every night, which is self-destructive and generally destructive to a relationship, why would I want the same thing for, for my health?'*

There was a recognition that the optional nature of current offerings of structured education may diminish motivation to attend.

> *6003 "if you give people too much choice-, They feel lost. If you give people a limited choice-, you know, you're f-, you're almost forcing their hand a bit, in, in a positive way."*

Many see the benefit of group education if it could be delivered in a more individualised way, bringing them into groups with people like them.

> *1085 "I like the idea of being in groups, because-, it's like I was talk-, talking about earlier, it's just nice to talk to other people who have-, who have the same issues as you or-,"*

> *6003 "I think when you're in that group of-, amongst a group of people like that, it, it has a really, really beneficial effect."*

Healthcare professionals' perceived attitude and behaviours play an important role for this group, as its members need to feel safe to ask questions and trust the advice given by HCPs with whom they have been able to build a relationship.

> *1505 "So she talks to me like a human being as opposed to like a five-year-old child, so-, Umm, she just tells me how it is and, yes, she sometimes makes suggestions, and I'm quite happy to listen. I'm not against people giving me ideas, but-, Umm, she just, she talks to me, like, sort of two adults talking to each other."*

For some however DAFNE will never be perceived appropriate.

> *1505 "It's kind of a bit of a double-edged sword, really, (laughter), because, sort of, I want the stuff [educational content], but I don't want to go, and there seems to be, sort of, myself*

and the, the system, we're at opposite ends of the spectrum, there doesn't seem to be any way of compromising in between"

The type Bs were characterised by an educational and numerical ability to manage FIIT. They had sufficient diabetes knowledge and skill to moderate their self-management; avoiding acute complications without allowing diabetes to significantly impact on their day to day lives. They felt judged by others about the way that they managed their diabetes, and were therefore managing it for others, but with little support (either from loved ones or HCPs). They quoted time and work commitments as reasons for non-attendance at DAFNE, however the biggest barrier appeared to be inability to prioritise attendance and disturb the status quo. For this reason, I have named this group 'not yetters' as they would be suited to DAFNE once they have found the motivation to attend.

12.3.3 Type C:

Five (excluding outlier) of the twenty-five interviewees were classified as type C. The type Cs were defined primarily by their **low numeracy** making them unable to cope with the concepts required for insulin dose adjustment.

6002 "I'm not very good at maths, but I, you know, I can, I can do a few numbers… My decimals are not the best but yeah (laughter). I get out my phone and calculator."

1374 "I'm not good at maths at all, so… I just-, just normal, simple maths."

1134 "Umm, I was a little bit of a troublemaker (laughter). Umm, yeah, a little bit of a troublemaker, a clown, and everything, because… I did, umm, didn't like it that much, umm. I liked a few classes, a few of them, but, like, not all the classes… I'm not good with maths that much, but, depending on how they explained it..."

It also meant that some of them were less able to calculate the risk associated with their diabetes, which influenced their decision making around diabetes self-care.

1374 "Well, obviously, like, if it's really high-, That's when the complications can start. ***But what's really high?*** *Err, 11, 12, 15…HbA1c… Honestly, everything can improve, but for me, I'm happy with where I'm at now [glycaemic control]". (HbA1c of interviewee 9%)*

Many of them had insight into the issues that their low numeracy might raise if they tried to perform insulin dose adjustment.

1798 "Oh, it's a half insulin. But I, I've got 15 halves, haven't I? Because I, it's-, err, it's half to ten, and three of that, so it's one-and-a-half…Sorry, sorry… Yes, I see what you mean,

you've got to think about-... these, not my strong point, as you can see… Yes, yes, I'm not very bright."

6002 "Because it's the way the, the carbohydrates are being counted, to me, that, err, when I was with the dietician, it took me quite a few good minutes to really understand-, When I went home, I still did not understand, I had forgotten what we were doing… The hospital was fine for, like, ten minutes. After ten minutes, when I got home and tried it, and, I, I was not getting it."

1114 "I'm alright with maths, but, umm, I wouldn't say I'm 100% perfect with it. I'm alright with it, but just as I said, no, I might make some maths calculations go wrong there, and take the wrong amount of dosage, and then-, Thereas, I'd be suffering a hypo, or I have-, I've eaten too much and didn't-, hadn't taken enough insulin-, That's another, umm, factor that's in it, with me and maths, maybe another problem there. It's why, yet again, I'm just so used to taking my set amount."

Because the majority were aware of their short-comings, they **lacked confidence** in their own ability.

1798 "Umm, no, I mean, maths is not my strong-, no, I just have to think, and be reassured that I've got it right, I think."

1114 "But I shocked myself that I managed to bring it [HbA1c] down a little bit more closer to the right range."

1134 "-, I-, we get, umm, appointments and everything, but I need to know, like, what I'm actually doing to myself, if, like, I've done something wrong- I've done something, maybe, good, at least, like to, maybe, help myself, or maybe put myself-, keep myself out of hospital."

1114 "I can see myself messing up somewhere along the line, and not take the right amount and my sugar levels will always be high, I never have a chance to be at the right level, or maybe be high once, and then come back down. I think it will just be more complicated for me, to be honest."

Their insight into their numeracy and low self-confidence meant that they were **not keen to experiment** and preferred the rigidity of fixed insulin doses.

1114 "I never learnt to take, say, carbohydrates, certain amount of-, was inside, I didn't know to take 10 units because of that, and the chicken had such-and-such in it… I never learnt to calculate that… Umm, they wanted me to go on certain courses… I didn't want to, because I'm so used to taking the set amount… I'm just so used to, I mean, like I've been I've been a diabetic since 2005, and I've just been set in my ways of taking that set amount, and that's what I've just learnt to do… I'm so used to that routine."

1114 "Umm, I'm just happy with the set amount. I don't like to have to break it down, or take it five times a day, umm, or anything. I just like taking it four times a day-, Set amount. Most of the time, that set amount is the correct amount for me to take with a meal… I'd say, it would be fine, my sugar levels, unless I had something sweet, but if I don't eat sweets my sugar levels would be fine, as far as I'm concerned."

1798 "I'm pretty rigid about the times of my insulin. You know, I stick to it… I'm very unadventurous in my diet, and I, I think, umm, some people think I stick too rigidly…I'm very conservative. I stick to what I know… So that if there's-, I, I, I suppose I think I don't want to, you know, sort of be experimenting with, you know, this or that."

*6002 "**Why do you feel that you've had to cut down on going out so much?** I would say because my sugar levels usually rise when, you know, I've, I've gone out… so the night-time is a bit, is not very good for me, because I'm always in the-, in and out of the toilet. And I don't want to change the doses of my insulin."*

1134 "Just stick to what I know, what I know so far, really… I don't know if I can really come out of the, the way I'm going right now. It's-, like, it's just been going on that, like, years now"

This unwillingness to experiment went further, with one interviewee showing resentment at having been given permission to dose adjust and take responsibility.

1114 "I can eat whatever I want, just as long as I take my insulin with it, with the right amount of dosage-… And my mum was like, 'Well, they shouldn't be telling you that, because that's slack'… I shouldn't really have been told that, but at the end of the day, it's down to me, I'm the individual, it's down to me to know not to do that… Just because your doctor said you can do der-der-der, you have your own sense to know that you shouldn't because you can't be trusted, basically."

Most of them easily recalled **negative experiences** of change, further bolstering their low self-efficacy.

1114 "Because I've made that fatal mistake once, I thought I was going to have time to have breakfast, took my insulin and had a hypo-,"

1798 "I did have one or two hypos, and they said, 'Stop banging', you know…'If your blood sugars start rising, don't, sort of, "Right, I'll give myself a jolly good dose… that will sort that out"', you know…'You've really got to be careful-'."

*6002 "There's a time I went up by, about 8 units. Yeah, I got a good old telling off, but it was still at 17. **So, who told you off?** …The diabetic nurse, yeah. She said I'd put the units, too many units..."*

1134 "I don't want to inject myself and then make it worse, and then I have to be back in hospital again-, I'm trying to stay out as much as I can, so-, ***Yeah. How many times have you been in hospital?*** *I've actually lost count, umm-, Probably over fifteen times-,"*

For the majority, the negative experiences were related to episodes of hypoglycaemia. This was therefore their greatest concern, giving their diabetes management a short-term focus on hypoglycaemia avoidance, rather than longer-term diabetes complications.

6002 "But if I'm going to eat less then I'd usually have-… I'd bring it down. ***So you wouldn't go up, but you would come down.*** *I would come down, yes.* ***Because you don't want to have a hypo?*** *Mmm, mmm."*

1374 "I'd rather be high than having a hypo... Hypos are just the worst sensation ever. ***So, do you think you tend to run your blood sugars a bit higher, to avoid-,*** *Err, yeah, yeah. And like, if I take too much I thought 'Uh-oh, not good', because I can quite easily go into a hypo"*

1134 "So I've just changed it down a little bit…I've been taught to change it, because I've come in before and, like, it was too low, and I had to be admitted to hospital, so… ***Mmm, so you prefer to have it a bit higher?*** *Yeah, a little bit higher-, Not too much so I have to be admitted, but low enough so I can not worry-, worry about it too much."*

1114 "But, umm, as I got older, I started to get it under control, and then through pregnancies, hypos are a lot more-, comes up a lot more, should I say, and, umm, I dealt with those. Now, it's probably more in the highs-,"

1796 "I don't like, you know, to have a hypo, you know what I mean, you know, because it take time to recover, and it's really make-, it makes you unwell… So I'd rather have my blood sugar high-, And then go [boating], you know, and I feel safe in that way."

The type Cs worked hard to do the tasks asked of them by their healthcare professionals, even though they often could not see any benefit in doing it.

1134 "Yeah, I have, umm, the book… They've given me, so each month, or day, go down and just write, umm, each day, what I've, what the reading was-,… If it was high or low-,… ***And do you ever look back over the blood sugar readings, and, like, have a look at it, and think, 'Ooh, that was a bit high, why was that so high?'*** *Umm, not really, like, because it's just, like, a few numbers…"*

1798 "They've had to reduce my insulin-… So I'm going into double figures more often now… but I mean, I'm on a quite rigid, umm, umm, dosage at the moment, which they want me to keep to. Umm, albeit it's going a bit higher than I would like."

6002 "Umm, I write down them… I've got a book, yeah… So, I'm between 15 and 17 in the mornings, so that's what it is... yeah, I've added a few units of insulin but, you know, it still stops at that 17-15… I don't know what to do next, yeah. So, mmm. It's like, I know what it is, what I'm going to, to be in the mornings…so I keep doing it [checking blood glucose], and do it, just to see if I'm going to reach that target they've told me at the hospital to reach… No, it is really hard. It's frustrating… Ahh-, it's just that, you know, when you want to reach a target, you just keep trying, you know?"

They rarely sought information for themselves, relying on others to provide it, even if they had questions or doubts about their current practice.

1798 "Well no, I would welcome any sort of information… that's going, yes, any sort of education... I, I would love more information, really, to get, because, you know, this whole Italian food thing, which I've got a huge prejudice against, but it's only because my lack of knowledge."

1798 "Umm, oh yes, I never particularly want to eat three Weetabix-… It's quite a lot. But, you know, I want to do the dance class, and so I just do it."

6002 "Yes. Some people stay slim, some people get fat. I don't know if it's true. Yeah, I've never asked anybody to see if insulin really makes you-,"

6002 "I, I don't looking for what to, you know. Because I already know what the diabetes is, and, umm-, yeah. I don't go and see further research or further informations, or further-, no. I just stick to what I know. I don't go investigating (laughter)."

1114 "…they have some leaflets there-, out in the waiting room... But, yet again, I don't really find myself finding out information about my diabetes... You know, that I found, a lot of bit more information, that I was told when I was pregnant, should have been told to me from the beginning… maybe in a couple of years' time, I may ask, you know, query if there's anything else new that's come out, or, yeah, more-, if there's any more information I need to know about diabetes-"

1134 "No. I haven't done any research or anything like that, just come to [hospital] and everything. It's basically word of mouth-, really, like, because you can't really believe everything you see on, like, the internet or anything like that, or on TV-… the ones [leaflets] I've been given by [hospital] here… I've just read through them, yeah… I don't, like, go back to them and read them or whatever, or anything like that… I've kept, err, that sheet-, It's on my wall at home-,"

Just as they relied on others to provide information, they were heavily supported by others with self-management decisions

1114 "…so then they would change it [insulin dose], and then when I come back in the following week or two, they'd be like, 'Okay, you know, that, that one worked, but let's look at your night-time one, there's a bit of a disruption going on there', you know, they may need to change that, bring it up higher or lower. And then, yet again, I come back in the following couple of weeks, and it's better…"

1798 "Well, I do consult the, umm, the, the, the staff at [hospital] about-, because, unfortunately, it doesn't stay static… And then when she [mother] died, my sugar levels just shot up… went into double figures… so I had to go and seek immediate help for that… go to the, err, next available diabetic nurse about the, sort of, emergency… I knew I had to in-, but I, I knew I needed support and supervision."

6002 "At least they know, you know, you're doing it, at the hospital… It [glucose meter] can check up on you and see how you're doing… Yeah, I'd feel, you know, they know what I'm doing so, you know-… They can advise me or-, Tell me what to do next, yeah."

1134 "Umm, my GP, or dieticians, or the nurses, umm, diabetes doctors… Different from-, advice from different people… I don't know what I'm doing myself, so they're the, the ones that are there to help other people…"

And were keen to have input from those around them

1134 "Everyone's looking out for me, looking after me, telling me how to control it and everything like that, so-,"

6002 "So it's umm, mmm. But people understand, everybody knows I've got it-, You know, my friends, family-,

1114 "I had my friends as well. It's not just my family, it's my friends as well that were supporting me, saying 'What are you doing? You're a diabetic. Can't have that, are you trying to kill yourself?... The fact that so many people that cared about me, kept on reminding me of the things that would happen if I don't take care of myself-,"

1134 "I don't know what I'm doing half the time-, So, it's all advice is welcome, really…"

This groups lack of self-confidence created an element of naivety, trusting almost all sources. They lacked the skill to filter information that the 'go-getters' and 'not yetters' appeared to have.

6002 "Mmm, someone told me I should try some Aloe Vera-,… So I take, I take a cup, a little cup of it every day."

1374 "But do you feel that you are able to get all of the information that you need online? I would say, yeah. Yeah. And you think you can trust everything that you read? Mmm. I don't say-, yeah. I mean, not 100%, but 99.9… I mean, the social media now, is like, it's amazing,

there's nothing you can not find and not know about. And it just keeps you, like, always in touch with everything."

They considered type 1 and type 2 diabetes the same disease, with no differentiation between the two.

1114 "No, because they're still diabetic. To me, Type 1, Type 2, they're literally the same. We've got the same thing."

1374 "Yeah. But I didn't really-, like, umm, after speaking to my mum, like, two of my uncles have diabetes Type 2 so-, I didn't know it ran in the family."

1374 "Like, my old colleague, they were Metformin, but like, with X now, he's umm, insulin-dependent, so-, We can relate even more-… at the end of the day, it's all diabetes-,"

For most type C's their motivation for carrying out self-management tasks was to please others

1114 "My mum, my uncle and my nan-, they're not very happy [with me]… and that's [glycaemic control] something that I'd like to work on them, bring it back down, make everybody happy with me."

1134 "I have had a few ups and downs with it, umm, bad thoughts, but I know I have to get on with it really, like try and be strong for myself and for my family and friends, really."

1134 "my family, I guess, like being, being able to see them, like not from my hospital bed, but outside, like, from the house-, Or like family parties, or birthday parties, or something like that. I don't want to put them in the situation where they're worrying about me all the time-, Like, I want them to see me well, see me happy, and everything like that-, Not, not having to worry about my healthiness, so."

Although some were trying to improve their diabetes care for themselves, they had a sense of disheartenment.

6002 "Yeah, I just want to find out how-, Yeah, how I can do better, yeah. Because it seems I've just failed (laughter). Three good years, I'm getting nowhere, yeah."

1374 "Nothing I can do about it [having diabetes], I don't really-, not care, but you know, it's just part of life..."

The **barriers** to attendance at SE for the type Cs were founded in their low numeracy and health literacy (as illustrated above). They appeared to have low self-confidence, making them risk averse and nervous of change. They appear to be working hard, but often didn't understand why they are

performing the daily self-management tasks which made them disheartened. They did not actively search out information and were heavily reliant on HCPs to provide diabetes information and make management decisions for them.

> *1374 "(Laughter), oh I don't want to be that precise. It's bad enough, just like, you know, having to do with it day-to-day… Yeah (laughter), like you know. You know, though, God, it's just like-, then you'd be just living for diabetes, you know. Diabetes can't control you, like you have to control it… But if I was to be so, like, anal and stuff. I'm not like-, yeah, I've got it, but, like, I want to live as well."*

In addition, they described some of the barriers seen in the other typologies, for example, being unable to prioritise over other commitments

> *1374 "Yeah, that is the only-, yeah. I, I just taught myself. Well, I mean, I know I should go to hospital more, but like, it's just so difficult as well, because of work, and I, I would love to go on one of the courses, but again, the courses run during the day, so it's just like, it's so, mmm, it's not feasible for me. Like, I know my boss would give me the time off but, I mean, it's quite a big chunk of time, and like-, I know it's not the right attitude, but anyway (laughter)... It should be valuable, but, umm, I'd rather be on holiday than-, or, or just being at work, than being on a course."*

> *6002 "I registered for it, first time I did, umm-, it was over a year ago. But, by the time I was supposed to go for it-, My mum passed away. Yeah, then I registered for it earlier this year. My daughter came down with a bug, so, yeah. So I had to cancel, and when she gets sick, she really gets sick. Yeah, so I had to pull out. So I've registered again."*

> *1798 "Yes, I mean, I applied, you see, because I was a carer… Looking after my Mum… At, umm, [hospital], was always keen for me to do the DAFNE course, and I said, 'As soon as I'm a free agent I'll do', so I did sign up and say, 'Yes-,'"*

> *1114 "because my children ain't in nursery and, as I said I like to bring them everywhere I go, which is not necessarily always good, but, umm, I like to bring my children wherever… I can get babysitters, but I like to be with my children, so I think that's something else, for why I say I'll wait a couple of years' time…"*

Some were concerned about group education and having to interact with other people with diabetes, mainly due to concern for others.

> *1114 "I'm the type of person that makes friends easily-, So I get, kind of, attached to certain people easily, and take on their problems… But also, at the same time, there's going to be me fretting and worrying about them."*

1374 "Umm, just meeting new people, diabetic-, because it, it does frighten me a little bit, to be fair, like, you know. You don't want to hear horror stories all the time (laughter)."

For some interviewees, it was healthcare professionals and past experiences that presented a barrier to attendance.

1798 "I don't get [hypoglycaemia] signals now, you see, that's the problem… I had to go and see the diabetic nurse again, because they, they're checking my blood sugars…I said, 'Oh well, I've received information about the DAFNE course and-,' and she said, 'No, don't do it at the moment, because we've got you in this-,' umm, but I mean, I'm on a quite rigid, umm, umm, dosage at the moment… So she said, 'Because of that-,' 'If you go to DAFNE, it will, it will confuse-, it's confusing for you.'."

1114 "I can't say if that is one of the reasons why I definitely don't want to go-, because they could admit me [to hospital for poor glycaemic control], but it's just a thought that may be running through my head" [based on previous experience during pregnancy]

All those interviewed freely admitted that they had numeracy issues, and were willing to learn. Therefore, they might be pleased to be offer further support, rather than insulted.

1134 "Well, we all need our education on it, like we're not professionals like the doctors, and everything like that, so we can't know what's going on inside us, so, obviously we need a little more information on what's going on inside us-,"

However, it would be worthwhile routinely measuring numeracy as one of the type Cs behaved more like a type B with multiple sources of information that she found for herself, particularly online. However, her self-sufficiency may have been detrimental as it gave her conviction that she could self-educate, but appeared to lack the ability to filter the information and digest it appropriately; as she translated her HbA1c 9% as not putting her at risk of complications (see previous quotes).

1374 "Umm, a lot of research again, on Google, I'll like, you know-, funnily enough, I do have quite a few colleagues that are diabetics… I like to go on, err, you know the meter companies and stuff… I get, like, little magazines and stuff (laughter)…I get a lot on my Facebook and stuff, and if I find it interesting I'll click on it, but otherwise... I'm not actually talking to other people… I like to look up my own things, and find out for myself."

Overall the type Cs showed a keenness to learn and attend SE

1798 "Well no, I would welcome any sort of information-,… That's going, yes, any sort of education."

6002 "I just like information. Yeah, just, just like to know a lot-, mmm. Especially if it concerns my health err-, Yeah, I, I would be interested"

1134 "I thought it was something good for me, yeah. Err, something to help, like, gain, gain more knowledge... But I would-, I would go to a DAFNE course, and everything, I would just have to get to used to it, I guess, like I have spoken about it before, with one-on-one with people, and-,"

Often their friends and family were involved in their care, and this may be an opportunity to educate the wider community, as well as providing additional support outside of the hospital setting.

1134 "So he's [brother] been there as well, and my parents have been there as well, when I needed something…Umm, I'm not sure they know too much about it in themselves… So I wouldn't know what they would tell me, really, but what I tell them is from the doctors"

It may also help them to filter out incorrect or unhelpful messages.

1374 "Yeah, but like nowadays there's just so much information out there-, That is good information, that realistically, a course-, yeah, could be beneficial, but not necessarily. If you really want to understand it, you'll make yourself understand it, and there's lots of help guides, and, and, and aids that will help you understand it, so"

Many of them could see the advantage of peer support and would welcome group education

6002 "I would like to meet more people… And find out, you know, their experiences, how they lead their life, what they do… Yeah. Just find out how they're coping."

1134 (sees value in mixed ability and group) "No, because, like he's got more experience than me, you know, like I've, I've still got years ahead of me to like, to go to find out what would happen in the future and everything like that, so he's already done his time, I guess, like, umm, getting the experience over the years, so it would be good to, like, gain some knowledge from him, and gain some knowledge from somebody else as well-,"

1114 "I like debates, you know, I like group things, umm, whether they're old, young, middle-aged, whatever, umm, man, woman, I don't really mind it…"

Consideration also needs to be given to the way that type Cs learn. None of those interviewed had completed higher education, some had been educated in another country or a few decades ago. They would need a course structured to provide content in the appropriate learning style.

They would need a very supported environment to help increase their self-confidence and allow more experimentation, with positive reinforcement of change and reflection to allow it to become a learned behaviour.

> *1114 "I believe instead of my three-months appointment or four-months appointment, if it was a little bit more closer together than, umm, I believe it would-, would also help me keep it in check."*

> *1134 "I haven't got that much self confidence… Err, so I just need to really push myself at the end of the day, to say that I need to go to this course, so-… I don't want my family pushing me to do it, because I know I will do it in my own, in my own time. I don't want to, like, be pushed to do it, like I'd-, I need to gain my own self-confidence. I don't want to pushed to do it, and then I back out at the last minute"*

> *1374 "I would do the course, and I would kind of forget about it, so-,… I mean, it might be like little bits and pieces that you remember-,…And then, like, with information, it's always, it's recycling, so whatever you're taking out from that course, probably two years down the line, it's irrelevant."*

> *1134 "So I would guess I would have to get used to testing, and taking my insulins five times a day, again, so-* ***Do you reckon it's likely that, that you would be able to do that?*** *I would have to get used to it again, umm, just remembering-, because I've gotten used to taking two now-, "*

The new technologies available to help people self-manage, such as bolus calculators may be of value or remote glucose monitoring.

> *1114 "… go online and do them things, and yes, store my sugar level readings. I think that's a bit more better than taking out the pen and paper and try and... If there was something quicker on my phone, because it's always in my pocket, it's quicker at hand… because I'm always on the phone, literally, I believe, umm, that's why it would be more usable for me-, to do the diabetes on the phone."*

Although it would be important not to isolate the older generation or those less information technology savvy.

> *1798 "Well, I've only had it [computer] six weeks, mind you, you know, and I'm still wanting to throw it out of the window sometimes. It's very frustrating isn't it, sometimes, when it, sort of, leaps about to things you don't want?"*

This environment would also need to support them to organise time to attend.

1134 "Umm, I thought it [DAFNE] was a good idea, because I was just starting out myself, so obviously I needed to learn about what I would be going through-,.. Umm, work, at the moment. Like, just getting time off-, And, like, booking it, and everything, so it's just work at the moment, really, getting in the way, because I work five days a week already-, So booking a week off just to do the course, it's pretty hard at the moment... I haven't been to all of them [appointments], because remembering to put in my phone as a reminder, like, getting a letter, saying that you didn't attend this, like-, Like, I do want to come to all of them as much-, As I can, but, err, if I'm at work…"

The type Cs were characterised by low numeracy and educational attainment. Their lack of diabetes knowledge meant that they were unable to find information for themselves, and were heavily reliant on those around them. They lacked the self-confidence required to use experimentation, having had previous negative experiences of trial and error. This made them nervous of taking personal responsibility, preferring rigidity of fixed dose insulin despite also wanting to reduce impact of their diabetes on themselves and loved ones. I labelled this group 'trodden downers' due to their low self-confidence preventing type Cs from taking control of their own diabetes.

12.3.4 Type D:

Type D constituted five (excluding one outlier) of the 25 people interviewed. They would have all fallen into one of the three other typologies were it not for their underlying psychological issues making them unable to move forward with their diabetes self-management.

The main issue for 'diabetes downers' was psychological which prevented them from caring from themselves and their diabetes. Although other types displayed psychological barriers to attendance, the type Ds emotional state was much more pronounced and aggressive. It took different guises; anger, denial, avoidance and hopelessness.

1732 "I've got, I've got this damned, infernal crap called diabetes Type 1-, and they can't get rid of it, and there's nothing I can do about it. So, I suppose it's put up with it and lump it, really."

1732 "I look at that the same way I've always looked at it [diabetes]… I ignore it… Simple as that, I ignore it… I don't want to understand it… Because it's a pain in the neck that I don't want."

2504 "You're on defence… I suppose that goes with the diabetes, I don't know, because I was never like that [before diagnosis] … And since that day I broke-, after that, I wasn't being polite no more... and I noticed it in myself… I suppose it felt good in a way. You know, you felt like were a god."

2504 "And, it's just a nightmare trying to compete with it, every day. Every day's a new day. One minute you're up, then you're down."

1527 "I couldn't cope, because of my job. One week I was doing night-, One week, afternoon-, And the night shift I couldn't cope. Umm, sometimes I eat night time, daytime sleep, err, shift pattern, I couldn't cope. And, s-, and, plus the stress. So I can't control, umm, taking time to do the insulin, and proper eat, proper food. I couldn't cope. And I feel-, and I feel-, I were-, a lot of tiredness, and I developed stress, depression."

1527 "If I have appointment, I worried. I don't sleep the night-, In the morning, I call them, I cancel."

*1527 "**So tell me, do you, umm, do you check your blood sugar?** I ignore it most of the time."*

2019 "I think it's at least partly because ever since I have been diagnosed with it, I've been struggling with the idea of having it at all. I know I have it, it's undeniably true, but, at the same time, I feel as though admitting it is like giving up… And the more I embrace it, err, and actively worked for, for it, it feels like losing."

2019 "And, umm, I, err, I have been s-, struggling with it ever since. Like, there have been a few short periods of time where, I had it under my control, but it always kept spiralling back down again. I'm not really sure. I've always been either dismissive or, not ignorant, but trying to ignore it? So, most of the time I either forget to take my injections, or take my blood sugars-, Or I just choose not to do it, because I feel like I can't be bothered."

*2059 "…but it's then, umm, arranging those appointments and, kind of-, sticking to them, and making sure I do actually go and not, kind of, putting it off… Umm, with DECS, so eye-screening, umm, I tend to put them off… And I, I have background retinopathy… So, umm, although I'm sure they would have given me time off, it was probably more that I didn't want to take it off myself... **Is that mainly… about not, not getting paid?** Umm, I think part of it was-, yeah. I think not entirely… I don't know. Maybe being apprehensive about going, and then again, maybe not having a good HbA1c, or-, having, if I haven't been testing regularly enough, then-,"*

Many of the type Ds had a long-standing diagnosis of diabetes (range 8-54 years) and talked about death being a better option. A few had even tried to commit suicide or had self-harmed.

1732 "You see, when I was younger, I always hoped diabetes would kill me, you know that?... Well, if I want the diabetes to kill me, I just either load up with a whole load of Actrapid-… And I thought, 'Knowing my luck, I'll wake up in the morning', so I tried it… so I can't even do that right."

2504 "like my doctor says, 'You're prone to have a stroke, you're prone to have an heart attack', I'm-, bring it on, tell me more, tell I'm, drop dead in the street', you know. What's the bother with it? It's going to happen anyway, I'll lose a finger, or an arm, or a leg. So, you know, give me the more good news. That's how I look at it, so you, you become very against it, with the-, denial, you think to yourself, 'I ain't got diabetes. If I want a jam doughnut, I'll have a jam doughnut'."

2504 "I wish I'd never had it. If I could-, if they said to me, 'We can get rid of your diabetes, but you got-, we got to take your arm off you', I'd say, 'Do it. Take me arm off. You take the whole, complete arm and, just as long as you get rid of the diabetes'. 'Give me my life back'. It interferes with everything."

Diabetes and depression was often blamed for other issues to do with their health or wider life.

1527 "Difficult time. And I have a marriage breakdown, a divorce. So, it put me, situation, you know, the, my depression never go away."

1527 "[erectile dysfunction medication] Didn't work for me. I told them, my doctor, he says, 'Because of your depression'. It's everything, the head, and this-,"

2504 "I don't like that weakness. I mean, even when you carry your meter around, people look at you, and you think to yourself, 'That's a-,' to me it's kind of a weakness, because if you ever get in any trouble, they think they can sort you out because you're ill, and because they can take advantage of you."

Despite their hatred/avoidance of the disease and what it meant to them, many continued to do some of the self-care processes required.

1732 "It gets worse, every year. It gets worse because I hate it that bad, and I hate doing injections. Err, I do one slow actor in the morning, 20 units, and then the Actrapid comes in whenever I eat-, So if I eat three or four times a day, I'm doing five shots a day."

1527 "Err, I do [take medications] once in the morning, or I do only the night. I'm quite depressed, I hate all my medications, to be honest."

2019 "I don't really mind the injections at all, although I do mind, err, taking my blood sugar… I don't, I don't really have a problem with the injections themselves, it's the fact that it's mandatory. That really, really annoys me."

2504 "It's like, you get-, err, it's like, how can I put it, it's like having a baby. You've got to, you've got to take care of it, every single minute of the day… I'm not too good with it. I mean, sometimes I'll do a test."

They were insightful as to how they should be managing their diabetes, often with strategies to help them.

1527 "When I see 27 [on glucose meter] I increase my, umm, up to 16 unit. ***Which one's that that you-?*** *Err, NovoRapid. Because I don't eat a lot, I can't take more NovoRapid."*

2059 "I just leave-, sometimes what I do is, umm, I will leave the needles I need for the rest of the day within my, kind of, pen case-, So, umm, I know there is, kind of, a reminder that that's how many injections I have left-,"

2504 "It's one and a half units, or 2 units. Pot noodles-, so it tells you in the book, all what it goes through, all the way through to pasta-… That's like my bible, that is… I've wrote, wrote it down on a bit of paper, so I can memorise, and save me going through the book."

2019 "I would say that I'm experienced enough to be able to, umm, err, to be able to have an accurate guess, err, an estimate of what, of, of what I need to inject, e-, even with dishes, or of foods that I've never had before… whenever I, err, said I could do carb-counting, the doctors seemed impressed, so maybe I could help other people with carb-counting."

But were often demoralised, had had negative experiences of trying or were just unable to drive themselves to do it.

2059 "Yeah, yeah, it's-, although with mine [glucose meter], it's generally above [target] (laughter) so it can be a bit demoralising, but, umm, yeah… umm, but I'm aware that, I guess, the nurses and GPs can't really help me-, unless I am testing to see if-, they've got nothing to go on-,"

*1732 "****What is it that's putting you off checking your blood sugars?*** *I think it's a pure and utter complete waste of space. Well, it is for me.* ***Why is that?*** *Because I used to check them, a long time ago… So I checked it. And it was at-, as it usually was in those days, it was through the roof-… So I did a shot… I was looking at the car in front of me. And that's the last thing I remember… [had a hypoglycaemic event and road traffic accident]"*

2019 "I have to think, err, that I need to find a place to inject first, then I-, 'I've never had thing before, how, how, how much should need to inject for this? Err, will it be too much or too little? And, oh, oh, I forgot my needles, they're still at home', and just things like that. ***Mmm, so occasionally, when you want to inject, is it not possible because you don't have all of your stuff with you, And how does that make you feel?*** *Oh, just unlucky, I guess. If I have-, because if haven't left it at home on purpose, then obviously I just forgot… When, when something bad happens, it tends to put me off… And then that snowballs and snowballs, and it gets even worse."*

1732 "They [peers] play the game exactly the way they should do, and they're still having hypos. They are still having problems. They are still getting their feet problems, and their leg problems. And they play by the rules."

For most of them the motivation to look after their diabetes was avoiding hospitalisation (although most had been hospitalised for their diabetes at least once). They therefore performed 'damage limitation'; doing the least possible to avoid acute complication and erring on the side of hyperglycaemia.

1527 "I try my best. Sometimes, if I can't take it, I take couple of Met-, Metformin-, And then, in the evening, I take the injection. I don't-, I don't actually follow the rules, you know, the how to do the, proper diet."

2504 "I don't want to end in hospital, because I don't like hospitals. We're not good buddies, me and hospitals, we don't get on… I'm not worried, I'm not worried about death, I've seen too much of it anyway… so what, if I drop dead, at least I'll be out of this place, wouldn't it? No, no more moaning, no more, di-, no more diabetes ever again."

1732 "Yeah, I mean, if I don't do my shots, then it goes from one extreme to the other. I'm either hypo-… Or, if I don't do injections, I'm steaming oversugared, and I'm out cold anyway. And then I've got an ambulance crew- trying to get into my flat… What choice have you got?"

1732 "I'm taking insulin. Which will cover at least half of the sugar load, even if it's 8 units, it's going to cover half of the sugar intake…"

*2019 "**What is it that motivates you to do that [take long-acting insulin], then?** Umm, because I know if I don't do that, then I will experience the adverse effects much, much sooner… **When you say 'the adverse effects', you mean the kind of short-term adverse effects, or are you talking about the long-term effects as well?** That depends. How long is long-term? (Laughter). Like by 'long-term', I mean anything that's severe enough to have to call emergency services. Sort of like, ketones and etc., I don't mean the extremely long-term effects, like, loss of sight-,"*

*2059 "**And, how confident do you feel changing your doses?** Umm, within a small amount, I mean, it's not so bad, especially if my levels are higher-, Then I kind of think that it's, kind of, less of a risk of then having, like, a hypo."*

They were aware that they were doing the minimum required and some had feelings of fatalism or felt that it was out of their control.

1732 "I don't know. Somebody's controlling my diabetes, but it's not me. ***Who do you think it is?*** *I got no idea. Somebody's looking after me, because I'd never bother…. you can't take control of diabetes."*

1732 "No, I mean, I think with life, err, doesn't matter what state you're in-, health-wise, or physically, or anything else, umm-, I know it sounds a, a strange thing to say, but everybody is given a set time."

1796 "…because my HbA1 is always high-, for how many years, ever since, you know, I start-, I was diagnosed, you know, the diabetes. And…I don't have the-, complications, that sort of thing, maybe, I'm said I'm lucky, or maybe it will come one day, you know?... ***And the complications, does that scare you, make you nervous?...*** *No. Because what, err, I thought if-, whatever happens, you know what I mean, happen. I just want to enjoy life, that's it."*

1527 "Yeah, but nothing I can do, it's something eating me, the diabetes. ***Why do you think there's nothing you can do?*** *I don't know. I try. It's something I have to keep it, that way, follow it, but I can't do it."*

2019 "Yeah, I do know it's up to me to do it, I mean, the, the doctors and my mum, they can nag me all they, all they want, but it's, it is my responsibility, I know that much, it's just that I can't bring myself to do it, and I don't see how I can make myself want to bring myself to do it-."

2019 "Err, pfff, the answer is obvious, I should take proper control of my diabetes. I, I know I should. I really want to, but, like, when the time comes for me to actually do it, I just can't get myself to do it."

They were often aware of the mistakes they were making but were unable to drive themselves to change or plan.

1527 "Err, if I got a meal, I can't finish, and my meal, two, three, four spoon. I depressed, I don't know, something is not me. I stop eating. And then I get, later, a hypo."

1796 "But because I don't inject during the midday-, or before lunch-, that's why, you know, my blood sugar, you know, goes up in the evening."

2504 "Then you're drinking something, trying to get yourself back, so you, you're forever, like, hitting the floor, hitting the ceiling. Hitting the floor, hitting the ceiling. Trying to get it in that mid-range."

2019 "I, I tend to take, umm, err, I tend to, err, ignore my injections, because I, umm, I don't always have food or money on me, and if I inject then, then the chances of me getting a hypo, the low blood sugar, or higher, and if I can't eat something right there and then, I'll, I'll, I'll, umm, not-, I'll be in trouble."

Many of them talked about the **isolation** that they felt with their condition, often associated with feelings of stigma and shame.

1527 "I apply several jobs. They, they don't allow the people-, they don't-, they don't going to tell you straight away, but they don't want the people with the insulin."

1527 "I couldn't cope. You can't live-, if you-, you can't live someone if you don't have, if you cannot make any love. It's hard for me. Embarrassed. Make me isolated. ***Did you speak to her about it?*** *They don't care, so-,* ***Did you, did you speak to her about it?*** *No."*

1796 "When, when my friends, you know, found that I was diabetic, they never used to invite me like… to parties, and that sort of thing, you know. I think it's just because, you know, they lack, err, knowledge, information about diabetes"

1732 "They brought out diabetic sweets. You could only buy them out of a chemist. You couldn't buy them out of a sweet shop, they were out of a chemist… children are children-, they take the Michael out of you, you know?"

2504 "Then all the, all my friends, so-called friends-, All turned against me. 'X's getting the best treatment-,' 'Because he's got diabetes', and all this load of rubbish."

2504 "Out comes the pen, 'Hello, shhhh', you know, as you've got your pint in one hand and the needle in the other, and they're all looking at you, thinking, 'Oh my God, he's jacking up in the pub'. I've had that… In a pie and mash shop. They don't understand you got diabetes."

2504 "And, umm, my employers was not very good with me. They try and say to me, 'Go and eat a sandwich, and if you need to inject yourself, do it in the toilet'… So my, my work is very biased towards me… I had a lot of problems with them, and I was starting to rebel,"

They were often coping alone, with little support, dysfunctional relationships or negative influences.

1527 "My dad got it. And he's blind, now. ***And your mother, also?*** *Yes. She passed away, mum, because of diabetes."*

1527 "And no-one, no-one have got the time for you, sometimes it's hard for me."

1732 "I said, 'It is absolutely driving me crazy, I'm doing injections every day, and it's just driving me potty. So she [sister] said, 'Well you've done it this long'. She said, 'Why are you complaining now? It's a bit bloody late to complain now, isn't it?'."

2019 "We tended to move around quite a bit, so-, I would keep meeting all these new people, and all these new hospitals, have to tell my story over and over again to all of them, and-,

And it feels like I never get anywhere, because as soon as I start to see some signs of progress-, we move out again… (Laughter) it's my mum. She always finds some sort, some sort of issue with the houses we're in."

2019 "… Umm, I, umm, I suppose there could be more support, but I've never really asked for more support either, so-,"

2059 "So, we'd often, sort of, talk about things, but, umm, other than that, I generally, sort of, just managed it by myself, umm,… Although, I mean, I had-, I was living at home, so, umm, other people, kind of, talking to me about it, and asking, like supporting-,"

2504 "Umm, well, my GP wasn't very sympathetic. I was just devastated. Broke, broke-, yeah, I broke down in tears, I was devastated, absolutely shocked. It was, like, someone had just took the wind out of me sails."

2504 "It wasn't my doctor, turning round and saying, 'This is what you got to do, this is what's going to happen now', you know. No training, I never had no training for the first couple of years of that, nothing. I just jabbed myself, whatever."

Commonly the isolation was through personal choice, often driving friends and family away.

1527 "Everyone says, you know, some people, when they go out for conversation, talk, psychology is good for them, but every problem I have, I keep it myself… And the way I react, is I keep people away, 'Go home, stay away', and-,… Nothing I can do, nothing I can do. I don't-, I don't have to fight for some one-, my anger, my problem, my problem's my problem."

1732 "And he[housemate] said to me, he said 'I'll keep a check on'. I said, 'You don't keep a check on me, you don't do anything. You keep your nose out of my business, end of conversation, and leave it like that. And that's the way we left it. He never gets involved, he never got involved with my health situation."

2019 "No, I should, I should rephrase. I don't, I don't really feel alone, umm, with regards to my diabetes. I know that if I-, I know that at, at any time, if I ask for help, then people will listen-, And provide me with support. It's just that, when I say I feel alone, I, I mean I don't really talk about it with others much, which is exactly how I'd pick it anyway."

2019 "it's usually just 'Hey, how are your sugars going?' I, I tell them [family] it's fine-, regardless of whether or not it is fine."

2504 "That's why I don't choose to have a girlfriend, because I can't be doing all that explaining… Don't have no friends. Got no friends at all… I sit indoors and drink… When I used to go down the pub. But I haven't done that, go in the pub and inject myself and stuff."

This may be due to a sense of not wishing to burden them.

1732 "And that's a hell of a pain to go through. She's [Mother] working all day-, And then she comes home, and has to deal with all this... Umm, boiling syringes, needles, checking sugar in the urine-, making sure the injection was drawn up properly, no air bubbles in. She had to flick any air bubbles out-, and check everything, and then give me a shot, and then, 'What would you like to eat?'"

For most (three of five) numeracy was also an issue.

1527 "I couldn't calculate it. It's hard for me… Umm, I'm bad for the numeracy."

1732 "I mean, numbers are numbers and they're, they're only guidelines-, for the diabetic doctors, and yourselves, that you can go by."

*2504 "**So how old were you when you were diagnosed?** Oh, now you're asking something (laughter). I was-, maths ain't no very good, so 50 or so-, nine years was it, 2009? 10, 11, 12, 13, 14, 15-, I was 50-, 49, 48, 47, 46, 45, 44, something like that? 43, 44, I think?"*

Another, although extremely numerate, had underlying communication difficulties (with a possible diagnosis of Asperger's Syndrome) whilst others had low health literacy provided a barrier to diabetes self-management.

*1527 "My English?... I understand, more I understand than speaking… Something-, it's difficult. I ask them back. Sometimes I ignore that, I keep quiet, and go away. **So when, when do you ask back, and when do you ignore?** I don't know, sometimes-, it's my mistake, sometimes, err-, if it's a group, I don't-, I don't know, I don't know. No, it's-, it happens sometimes. You tell me some words, a lot of things, and I catch up, err, 80%, the other 20 I put in my pocket, (laughter), and I go-,"*

*1527 "They [HCPs] said write it, then I come. Small book, used to show them… up and down [blood sugars], and he's telling me, why you take, when you got the hypo, why you take the sugar. And I explained him why, because I've got the anxiety, the fear-, for this NovoRapid. And then, the person who will say to you, 'Look, take this, take this, when you take this, when you see this, okay, bye-,' **Do you feel that they understand you?** That's how they think, but I do-, I couldn't quite-, I didn't get it. **You don't understand-, what they're saying to you?** No. **And they don't check-, that you understand?** No.*

1732 "No, because all I need is it put in blunt English. I don't need a doctor to say to me, 'Oh, well, we've checked your cholesterol level, and-,' how does he know that I know what a cholesterol level is? He can be talking French… They all get flash, and they all get technical, and it goes over most patients' heads."

2504 "But even the machines, I mean, are quite hard to figure out. I mean, I've got new mach-, I had a machine… which does it all for you, basically. It tells you what units to put in… But now they've changed it over to grams, and I can't figure that one out. So I'm not bothering with it… Yeah, I've tried downloading apps and things like that, and some stuff, but I just couldn't never figure it out. Because I'm, I'm not, well, as I say, I'm not the brainiest of people when it comes to mathematics."

2504 "And you've cooked all your food, and you've got it on the table, and you've got to think, 'Right, one potato, 1 unit. So it's four potatoes, that's 4 units', and you've got sit there, you've got to work this all out, then do a test, and enter, find out on the meter you're, say, 9.8-, And then you put the carbs in, and it tells you, oh, inject 6 units. By the time you've done that, your dinner's getting cold."

For the type Ds the main **barrier** to attendance at SE was **psychological**. It is likely that they would be unable to progress their diabetes self-management until they could move out of a cycle of avoidant behaviour and denial.

As previously mentioned, without the psychological issues the type Ds would fall into one of the other typologies. Most had communication or numeracy issues making them potential 'trodden downers'. In addition to the psychological barriers, this group appeared to have similar barriers to attendance at SE as the other typologies, and would require similar strategies to overcome these. As these have been outlined above, in the other typologies, I have only presented the evidence for the psychological aspect of the type Ds typology and possible strategies.

Group education may not initially be appropriate for many of the type Ds, as there was a reluctance to spend much time in the presence of others, even if they also had diabetes.

1732 "Don't talk to diabetics, they're strange people, they've all got issues with diabetes… They're all crazy, like me. They must be, to put up with diabetes, you know? They've all got problems, and if you look at most diabetics, they look bloody sad and fed up…Err, and the four or five other people would drive me completely round the twist, sitting there whinging about their diabetes."

2019 ", it's just that I feel like there isn't anything for me to learn, and I don't, I don't feel comfortable just being in a group session, talking about it."

This was complicated by anxiety and shame in front of others.

2504 "Umm, I don't know, to be honest with you, I just, I just felt aggressive [during DAFNE]. I felt like, umm, how can I put it, overcrowded or something, you know, like being enclosed-…

It's like putting you on the spot… Makes you look stupid, makes you look like a fool…, I'm getting ready to get out of here by this time-"

Some were keen to attend and could see the benefit, but lacked the energy to take the first step or integrate the practices into daily life.

1527 "I will come [to DAFNE], I will come. ***Why, why would you come?*** *Oh, the only problem's I don't have the energy. I try to eat somewhere. I don't have the energy. I don't know, sometimes when I'm exhausted, I walk, five, five, five, less than five minute, I feel exhausted."*

2059 "I don't know-, I think-, I think it, it could be, and it-, I, I think I'm capable of making it beneficial, and getting, kind of, the most from it, umm, because I know if I do the course, I still, you know, there's a lot that I need to do myself, to kind of-, Put it into practice, and, you know, actually follow through with it, so, umm, yeah, I think-,… I think so. I think now I'm in a, kind of, more structured and better place than I was, umm, before, so I think I'm definitely capable of it."

Early support from the day of diagnosis might help people come to terms with their diagnosis.

1732 "Don't bother with the old boys. We're a waste of time. Most of us already know it, and we know nothing. But we get through. It's the youngsters you need to concentrate on… ***Do you think if somebody had done that for you-?*** *I probably would have been in a much better situation, sure."*

This need for support, particularly at times of transition, was illustrated by one interviewee (who was the only one in the group without an underlying numeracy/communication issue).

2059 "the waiting list [for DAFNE] where I was first diagnosed in X is quite bad… and then moving to university, but keeping my, umm, diabetes managed-, In X, umm, and not really being able to travel back-, To, kind of, do it, and then, umm, when I moved over-, I, I first was referred to somewhere in North London."

He recognised that his self-management had worsened when he moved away from home and had had a period of transition/instability.

*2059 "****So you think that (end of honeymoon) was a kind of tipping point for you?*** *Yeah. And I think, I think, as well, like, err, going to university as well, I think-… not having such a set, kind of, daily routine. Umm, and a kind of-, I guess, moving away from home and then, kind of, cooking my meals, and pizzas-, things like that.* ***Okay, and alcohol?*** *Yeah, yeah, (laughter) alcohol too, definitely. Doesn't help!"*

He was demoralised and therefore avoided self-care tasks.

> *2059 "And in the past couple of years, it's been more, kind of, lax, and bad, and not as regular, umm, so trying to make sure I test, umm, is important, but something I need to improve on, err, definitely… Umm, and then, before bed, umm, I think my levels tend to rise in the evening. So that's, again, when I don't usually test-"*

However, recent stability and support in his life was allowing him make positive changes and to see benefit in attending DAFNE.

> *2059 "So now I'm, kind of, finished and working, it's kind of-, yeah, having more routine, and trying to, kind of-, think about it a bit more."*

> *2059 "And today, err, so this morning they were quite high, umm, and one of my-, my manager, my line manager picked up on the fact that I was, kind of, not necessarily as li-, (laughter) like, lively, or, you know, my usual self, umm-, And was, you know, making sure that I was okay, and just saying that I need to-, if-, you know, if I need, umm, anything, or-, C-, I-, yeah, so yeah. They are, they are quite good at, umm-, and they're understanding, I suppose-,"*

> *2059 "But, umm, yeah, I, I guess-, if, if, if I knew it was something that I was going to do, like, umm, you know, take time off and, kind of, set it aside, I think that would be fine, kind of.* ***Do you think you would, do you think you would be able to take the time off?*** *If I take it as my own annual leave, then yeah… Umm, it's for my own benefit, so I guess, you know, it, it, it, it would be, you know, a small price to pay-,"*

Psychological barriers to managing their diabetes defined the Type Ds. This group avoided checking their blood sugars and insulin injections, doing the bear minimum to avoid hospitalisation. Teaching this group skills for FIIT would be of no value as they would be redundant and go unused. This group were isolated and alienated, often through choices associated with feelings of stigma. The overwhelming psychological barriers of depression, hatred and avoidance in the type Ds made me call them 'diabetes downers'

12.4 Key points & Discussion

The qualitative analysis identified four typologies; go-getters, not-yetters, trodden-downers and diabetes-downers, with 92% of the interviewees fitting clearly into these groups. Two interviewees had characteristics associated with two different types, indicating the natural variability of human beings and difficulties defining people by groups.

'Go-getters' (type A) made up 20% of interviewees. They were characterised by:

1. Capability both in terms of managing the numeracy involved with FIIT and having come to terms with their diagnosis to the extent of fully integrating it into their lives.
2. A confidence in own capability to gather information from multiple sources, decipher what is relevant and have the conviction to experiment.
3. Forward view that they do not want to have any regrets about the level of commitment they gave to achieving near excellent glycaemic control.

'Not yetters' (type B) accounted for 32% of interviewees. They had a long-standing diagnosis of diabetes, with the majority being diagnosed as children. They were identified by:

1. Having the skills required for intensive insulin management
2. Integrating their diabetes self-management into their lives, but management style being more second nature or casual than 'go-getters'
3. Not prioritising their diabetes and not seeing cause to break the status quo
4. having previous experiences of being judged by others, particularly healthcare professionals.

'Trodden downers' (type C) made up 20% of interviewees. They had low educational attainment and were often unemployed or in non-professional roles. The defining features for this group were:

1. Low numeracy and health literacy
2. Low self-confidence leading to nervousness of change
3. Hypoglycaemia averse management
4. A willingness to learn and desire to succeed and/or please others

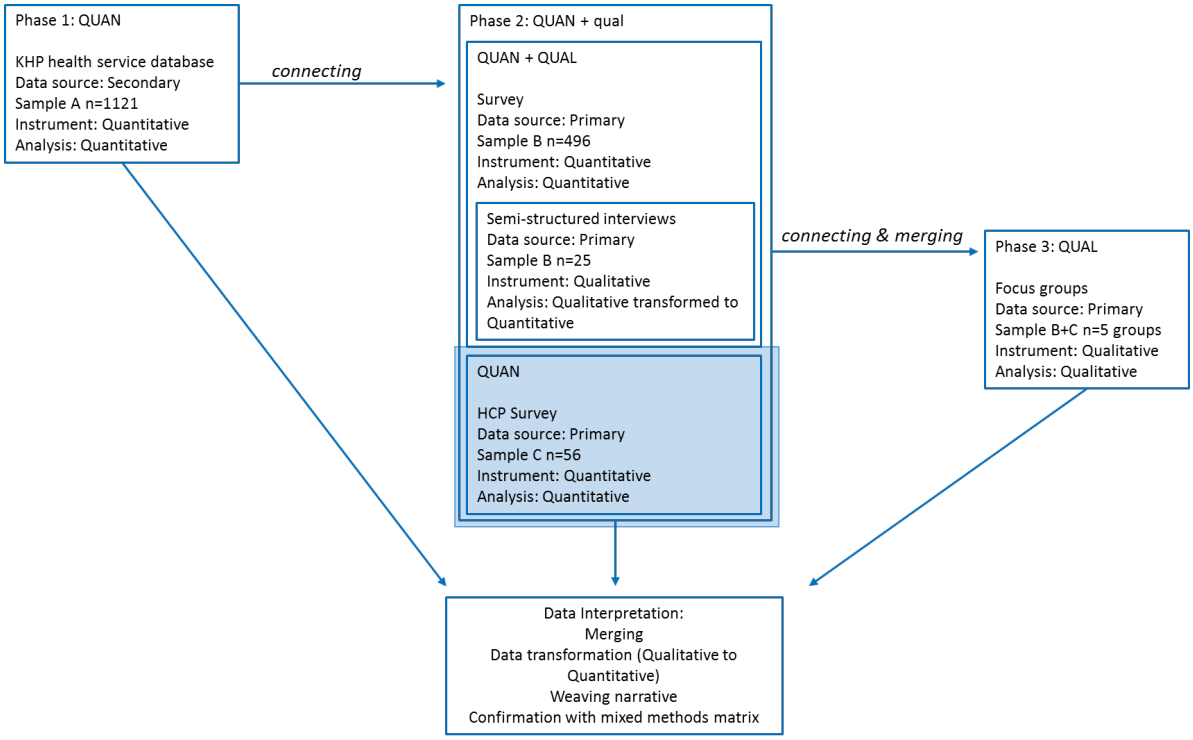
'Diabetes downers' (type D) made up 20% of interviewees. The characteristics of this group were:

1. Underlying hatred or denial of their diabetes
2. Avoidance of tasks associated with identifying themselves as having diabetes

3. Feelings of stigma or burden often with consequential alienation of themselves
4. Underlying numeracy or communication issues.

Different strategies need to be made avialable to enage people from the different types. With this in mind, I moved to the next stage ogf my project - conducting focus groups to seek solutions to the barriers indentified so far

13 Phase 2 Sample C: Healthcare professional Survey



13.1 Design and Results

In this chapter I will outline the HCP study, which uses a cross-sectional quantitative survey design to gather healthcare professional opinion and experience of SE for T1DM.

13.2 Analysis of HCP survey

The methods have already been outline (7.3.1.3) however iterative changes were necessary and are presented here. The recruitment process involved inviting local Southwark and Lambeth healthcare professionals to complete the online survey by email. To preserve anonymity of responses, reminder emails could not be targeted to individuals who did not complete the survey. Many emails returned with 'out of office' notices perhaps because people were on holiday (the initial email was sent in the summer) and many surveys were returned incomplete. Using, iterative measures to encourage greater response, a second survey was emailed, which had been shortened by removing the Diabetes Attitudes Score (DAS) and perception of number of people in clinic completing/awaiting SE. I also threw the net further to increase responses, and invited people from the wider South England diabetes teams to participate via local professional networks: South East Thames Diabetes Physicians Group, Dietitian group and Diabetes Nurse Specialist group. This increased the number of

responses (see below) but I am unable to comment on the response rate, as the number of people invited to respond is unknown.

In total 56 responses with more than fifty percent completion were received. This included 28 responses to the first questionnaire including the DAS and perceived proportion of people attending SE within their clinical practice.

13.2.1 Respondent characteristics

As shown in Table 13-1 there was a broad representation of the multi-disciplinary team amongst survey respondents. Healthcare professionals were only invited to complete the survey if they considered themselves to have a special clinical interest in people with T1DM. Primary care colleagues made up one quarter of respondents. 32 (57%) respondents were medically qualified, with 13 (40% of medically qualified respondents) currently in clinical training. About half of all respondents had a diabetes-specific qualification. PhD or MD degrees were not included as diabetes-specific, whereas MSc was. The recently introduced diabetes and endocrinology specific examination for speciality trainee physicians (MRCP D&E), was not included in the qualification options, so the number of respondents with this qualification was not captured, although the status of specialty training in diabetes was known.

Table 13-1: Frequency table of characteristics of respondents and scores on Likert-type scale (5 strongly agree to 1 strongly disagree) and Diabetes Attitudes Scale (DAS).
Categorical data shown as count and percentage (%). Continuous variables shown as median and inter-quartile range (IQR). Mean shown only for illustrative purposes where indicated. Statistical significance taken as p <0.05.).

Variable	
Place of work	
Primary	14 (25%)
Secondary	28 (50%)
Tertiary	14 (25%)
Job title	
Consultant	12 (21%)
Diabetes Specialist Nurse	10 (18%)
Speciality Trainee (Dr)	13 (23%)
Dietitian	6 (11%)
Psychologist	2 (4%)
General Practitioner	7 (12%)
Practice Nurse	6 (11%)
Number of years' experience	
<5	13 (23%)
5-10	15 (27%)
11-15	7 (13%)
>15	21 (38%)
Number of people with T1DM cared for per year	
<10	5 (9%)
11-50	18(32%)
51-100	7 (13%)
101-200	8 (14%)
>200	18 (32%)
Regularity of opportunity to discuss complex cases within MDT	
Daily	9 (16%)
Weekly	27 (48%)
Monthly	10 (18%)
Quarterly	6 (11%)
Annually	3 (5%)
Never	1 (2%)
Observed DAFNE – yes (n 55)	37 (67%)
Teach on DAFNE – yes (n 56)	16 (29%)
Highest diabetes-specific qualification	
None/non-specific	29 (53%)
ENB	5 (9%)
Warwick	6 (11%)
Diploma	5 (9%)
Certificate	6 (11%0
MSc/MEd	5 (9%)
Have you ever been taught specific communication skills for use in 'difficult consultations'?	
Yes	45 (80%)
No	7 (13%)
Unsure	4 (7%)

Variable	
How confident are you that you can identify patients with low health literacy?	
Never	
Rarely	0
Sometimes	0
Usually	10 (18%)
Always	39 (70%)
	6 (11%)
How often do you consider a person's literacy skills when advising a therapy?	
Never	0
Rarely	2 (4%)
Sometimes	7 (13%)
Usually	28 (50%)
Always	18 (32%)
People with T1DM are capable of self-management? (0-5) (n29)	5 (4-5) 4.5 +/- 0.1
How important do you think self-management is for your type 1 diabetic patients? (0-5) (n56)	5 (5-5) 5 +/-0.1
How effective do you feel current structured education programmes are at facilitating patient self-management? (0-5) (n 56)	4 (4-4.7.5) 4.1 +/-0.7
Percent DAS (n 29)	83% (78-86)
Patient autonomy DAS subscale (n29)	84% (78-90)

Half (51%) of respondents had more than ten years' clinical experience in diabetes. There was a broad mixture of number of patients cared for with T1DM per year, and the majority (64%) of respondents had opportunity to discuss complex cases with a multi-disciplinary team at least weekly. However, 18% (9) of respondents could only discuss complex cases quarterly or less. Two thirds of respondents had observed a DAFNE course, with almost one third teaching on the DAFNE course

13.2.2 Barriers and Enablers

Healthcare professionals were asked to give up to three reasons for low attendance at DAFNE. These open responses were coded in an iterative manner, using the methods outlined in Table 7-1. Not all healthcare professionals gave three answers, with the majority giving two or more. The first response was coded in the manner described, and additional responses reviewed for any new themes that were not captured within the current coding scheme. The coding scheme, shown in

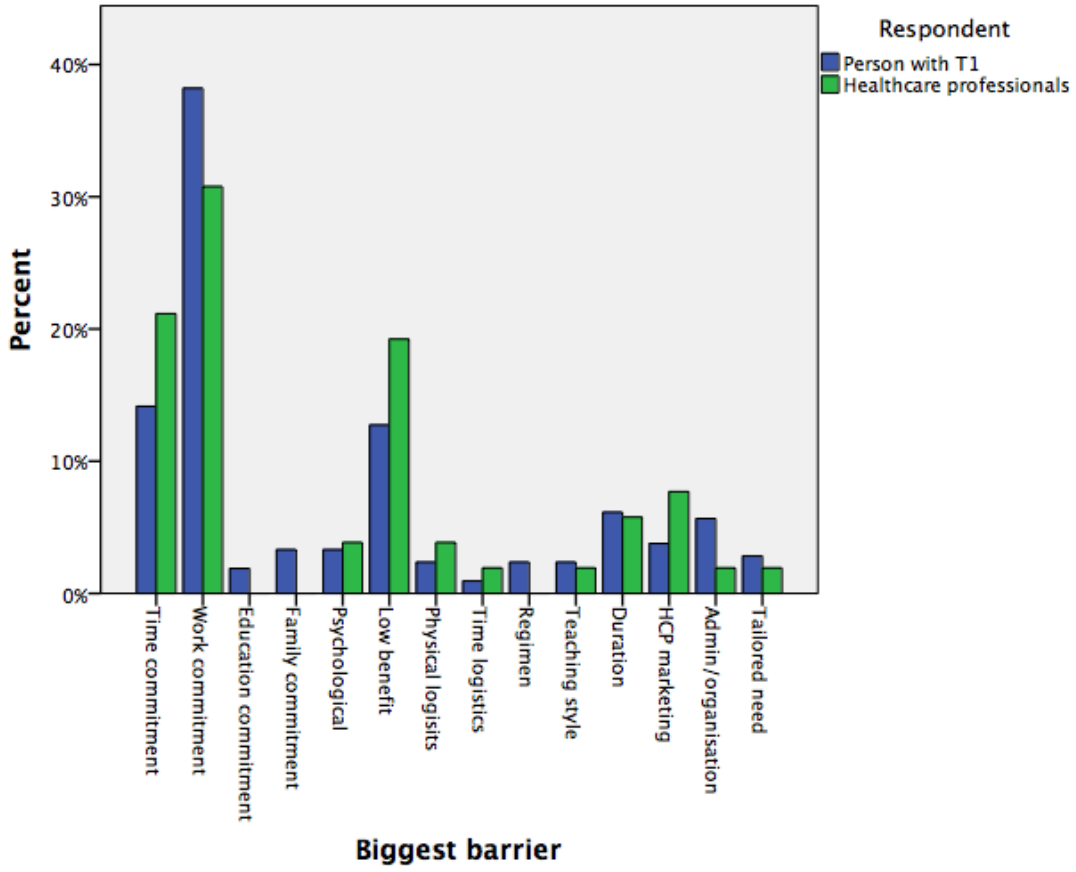
Table 13-2, was based on that created for the patient (Sample B) survey. Not all codes were needed for the healthcare professionals survey with childcare and educational commitment not being used. Additionally, low benefit (knowledge) and low benefit (control) were merged and an additional category of low motivation created. Tailored need was merged and a category 'availability' created. The need to add availability reflects Sample C coming from a wider geography, where some Trusts do not provide DAFNE on a monthly basis, if at all. Three iterations of the coding matrix were tested on the data by the research team, with eventual inter-rater correlation (across all 3 members) of 77%.

Table 13-2: Table of codes assigned to open responses from healthcare professionals to the question 'Only 30% of type 1 diabetics in Southwark and Lambeth have completed a DAFNE course. Give up to three reasons for this.'. Count of responses for each category shown, with percentage in parenthesis. Quotes taken from survey responses shown for illustration of coding process.

Biggest barrier	Count (%)	Example quotes
Time commitment	11 (20%)	*Time-can't take a whole week out although there is also a 5 x 1 DAFNE* *Time commitment (including labelling themselves as different if they have to take time off work even if employer agrees, or problems getting childcare)*
Work commitment	16 (29%)	*pressures of living in an advanced consumer capitalist society and demands for attendance at workplace* *Time commitment as one week and cannot get off work* *employment/financial*
Psychological	2 (4%)	*Difficulty coming to terms with dx [diagnosis] and diabetes self-care tasks (adjustment)*
Low Motivation	6 (11%)	*Readiness to change* *Lack of self- motivation in achieving better control*
Low benefit	4 (7%)	*Don't see DAFNE as important as don't understand the implications of poor glycaemic control* *Failure to be convinced of its relevance to them*
Physical logistics	2 (4%)	*Not local to the patient* *transience-moved into area*
Time logistics	1 (2%)	*timing of course*
Teaching style	1 (2%)	*Being worried that it would be too much school and they would not be able to manage it*
Duration	3 (5%)	*they think that a week's course is too long even though it will help them for the rest of their lives* *5 day length*
Advertising/Marketing	4 (7%)	*Not been given enough info on the course by HCPs* *Lack of HCP encouragement to attend*
Organisation/Administration	1 (2%)	*clinician forgets to refer*
Availability	3 (5%)	*Lack of courses/places* *Diagnosed prior to regular structured patient education*
Tailored need	1 (2%)	*language barriers*
Uncodable	1 (2%)	

Table 13-2 illustrates the coding matrix with quotations taken directly from the healthcare professional responses. It is plain to see that there is a degree of overlap between some of the categories, and without further discussion it is hard to tease out the relationship between constructs such as inability of a healthcare professional to convince their patient of the need (HCP marketing/advertising) versus the person with diabetes not valuing the benefit for the amount of time required off work (Low benefit) or not feeling the need to concentrate this amount of effort on their diabetes control (Low motivation). These are all very closely related; enabling movement towards patient activation to see the value and prioritise the course over all else. In this way, these concepts are interlinked with time or work commitments. If people were able to see the benefit of the course, because they had all the information required to measure the benefit, and felt activated and motivated to attend they would prioritise it over attendance at work and other financial restraints. Thus, time commitments are related to marketing and perceived benefit.

Figure 13-1: Bar chart showing the reasons for non-attendance at SE given by non-attenders at SE (dark blue) and healthcare professionals (green).
Percentage of respondents shown for ease of comparison. Note slight difference in categories; with merger of tailored need and low benefit, plus availability removed as not a response for Sample B.



Keeping the coding matrix for Sample C as similar as possible to that of Sample B allowed better visual comparison between the perceived barriers of healthcare professionals and their patients (Figure 13-1). There appears to be similarities between the proportion of barriers quoted by both

4111 those with diabetes and their HCPs. However, HCPs were asked what they thought was the barrier
4112 that they hear or see most regularly. Two thirds of HCPs correctly identified the three most common
4113 patient barriers to attendance (taken from Sample B survey); work commitment, time commitment
4114 and low benefit (control) (in order of frequency). Work commitment was second most quoted
4115 perceived barrier by HCPs, recognised by 29% of respondents. Time commitment and low
4116 motivation ranked first and third in HCP perceived barriers. Organisation/administration of the
4117 course does not appear in the top five barriers quoted by healthcare professionals, in contrast to
4118 their patients.

Table 13-3: Table of codes assigned to open responses from healthcare professionals to the question 'Considering your patients who have never been referred/attended DAFNE or similar, why you think this is?'. The first response was used only, as described in methods. Count of responses for each category shown, with percentage in parenthesis. Quotes taken from open question survey responses shown for illustration of coding process.

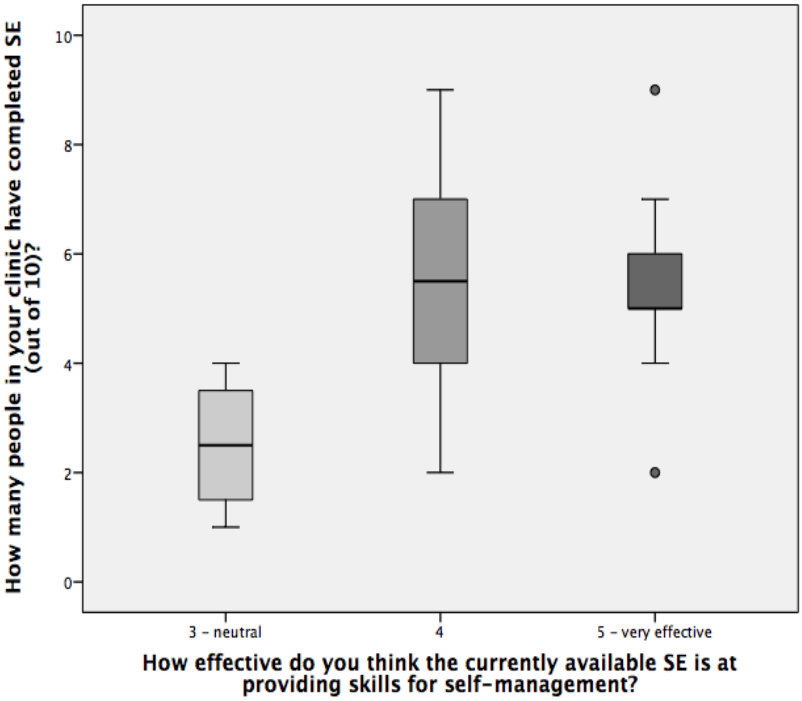
Suggestions for change	Count (%)	Example quotes
Work commitment	8 (14%)	*get the government to make it mandatory and for employers to give them 'study leave'* *Greater help with "industrial relations" helping patients to liaise with their employers to allow time off for DAFNE* *Legislation to enforce employers to allow time off to attend after diagnosis.*
Low Motivation	1 (2%)	*Some sort of incentive scheme?*
Physical logistics	1 (2%)	*Hold the education nearer to the patient - GP surgeries*
Time logistics	8 (14%)	*Try a week end course?? (though we have previously had week end clinics but they are not well attended)*
Teaching style	2 (4%)	*using technology to de-mystify the maths and simplify the dose calculations* *Offer one to 1*
Duration	3 (5%)	*Provide an intensive version with shorter duration* *Tricky but reduce number of days and do a condensed version*
Advertising/Marketing	16 (30%)	*lobbying the DoH [Department of Health] to heighten importance of structured education* *HCP awareness*
Organisation/Administration	8 (14%)	*Explain at diagnosis that attendance is part of type 1 pathway* *Described and patient booked places as routine management rather than description as optional*
Availability	1 (2%)	*more availability of slots*
Tailored need	2 (4%)	*catering for the diverse client group* *In Portuguese and Spanish*
Peer Marketing	5 (9%)	*patients that have completed promoting it first hand in taster workshops / waiting areas to other Type 1s* *Peer to peer information: personal experience of people who have done DAFNE available online (e.g. Talking Heads/video shorts, blogs)* *More family and friend's motivation used for encouragement*
Uncodable	1 (2%)	

The recommendations for change were analysed in a similar way to the Sample B surveys. The first response was taken and coded according to the matrix by two members of the research team. Again, this was an iterative process, so the matrix is slightly different from that used in Sample B. Table 13-3 illustrates the proportion of healthcare professionals quoting each recommended change, with a selection of quotes taken from the survey. The most popular suggestions for improvement were making better accommodation for work commitment, time logistics, marketing or advertising, including peer marketing, and organisation or administration.

13.2.3 Analysis according to reported rates of attendance at DAFNE

As this study is aiming to identify reasons for low attendance rates, an exploratory analysis was carried out according to number of people reported to have attended DAFNE within each HCPs practice. Only 29 respondents completed the questions about their clinic activity, as it was not included in the second edition survey, therefore the analysis was underpowered and results are translated with this in mind. Analysis according to number of reported people attending DAFNE showed that there was an association between belief in DAFNE providing skills required to self-care and reported attendance rates; those with greater belief in DAFNE reported higher attendance rates ($p=0.04$) (See Figure 13-2).

Figure 13-2: Box and whisker plot showing the relationship between the respondents belief in the currently available SE providing skills for self-management, and the number of people within their diabetes clinic who have completed SE. The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the results with outliers illustrated individually with circle. Statistical significance taken as p <0.05



There was global over-estimation of the number of people attending DAFNE, with an average reported attendance rate of 50%. Given that this was far removed from reality of 27% the actual figure was felt to be of limited value, but a better marker of attendance was centile or ranking according to peers. Therefore, respondents were divided according to above or below average reported attendance (mean 5.03, median 5). The univariate analysis according to above or below average completion of SE in respondent's clinical setting is shown in Table 13-4.

*Table 13-4: Univariate analysis of respondents with above and below average reported DAFNE attendance rates, showing characteristics along with scores on Likert-type scale and Diabetes Attitudes Scale (DAS). Categorical data shown as count and percentage (%). Continuous variables shown as median and inter-quartile range (IQR). Statistical significance taken as p <0.05. *constant with above average attendance.*

Variable	Below average attendance n17	Above average attendance n12	p value
Place of work			0.07
Primary	6 (36%)	0	
Secondary	6 (36%)	7 (58%)	
Tertiary	5 (29%)	5 (42%)	
Job title			0.06
Consultant	2 (12%)	5 (42%)	
Diabetes Specialist Nurse	3 (18%)	3 (25%)	
Speciality Trainee (Dr)	3 (18%)	1 (8%)	
Dietitian	4 (24%)	1 (8%)	
Pyschologist	0	2 (17%)	
General Practitioner	5 (29%)	0	
Number of years' experience			0.016
<5	2 (12%)	4 (33%)	
5-10	9 (53%)	0	
11-15	3 (18%)	2 (17%)	
>15	3 (18%)	6 (50%)	
Number of people with T1 cared for per year			0.05
<10	2 (12%)	0 (0%)	
11-50	7 (41%)	2 (17%)	
51-100	0	3 (25%)	
101-200	4 (24%)	1 (8%)	
>201	4 (24%)	6 (50%)	
Observed DAFNE - yes	12 (70%)	11 (91%)	0.17
Teach on DAFNE – yes	6 (35%)	5 (42%)	0.73
Specific communication skills			0.19
Yes	13 (77%)	12 (100%)	
No	3 (18%)		
Unsure	1 (6%)		
Able to identify people with low HL			
Sometimes	3 (18%)	4 (33%)	0.62
Usually	12 (71%)	7 (58%)	
Always	2 (12%)	1 (8%)	
How important do you think self-management is for your type 1 diabetic patients? (0-5)	5 (5-5)	5 (5-5*)	0.81
How effective do you feel current structured education programmes are at facilitating patient self-management? (0-5)	4 (3.5-5)	4 (4-5)	see Figure 13-2
Percent DAS-3 (%)	83% (76-86)	81% (78-87)	0.88
Patient autonomy DAS subscale (%)	88% (80-90)	84% (76-91)	0.59

Table 13-4 shows minimal differences between respondents with high and low attendance rates, likely due to lack of power. There is no difference seen between those with high and low attendance rates for DAS-3 or patient autonomy subscale, belief in self-care or the skills provided by DAFNE, nor ability to recognise HL issues. The only variable showing any significant difference is number of years in practice. Figure 13-3 illustrates two thirds of respondents reporting higher attendance have been in practice more than 10 years, compared to respondents in the lower attendance group where 65% have been practicing under 10 years (p=0.016). If place of work is re-categorised into 2 groups; primary and specialist care, the attendance rate becomes statistically significant, with below average attendance for 100% of primary care workers versus 48% of specialist care workers (p=0.028).

Figure 13-3: Bar chart illustrating percentage of respondents with above or below average reported attendance at DAFNE according to number of years working experience.
Statistical significance taken as <0.05.

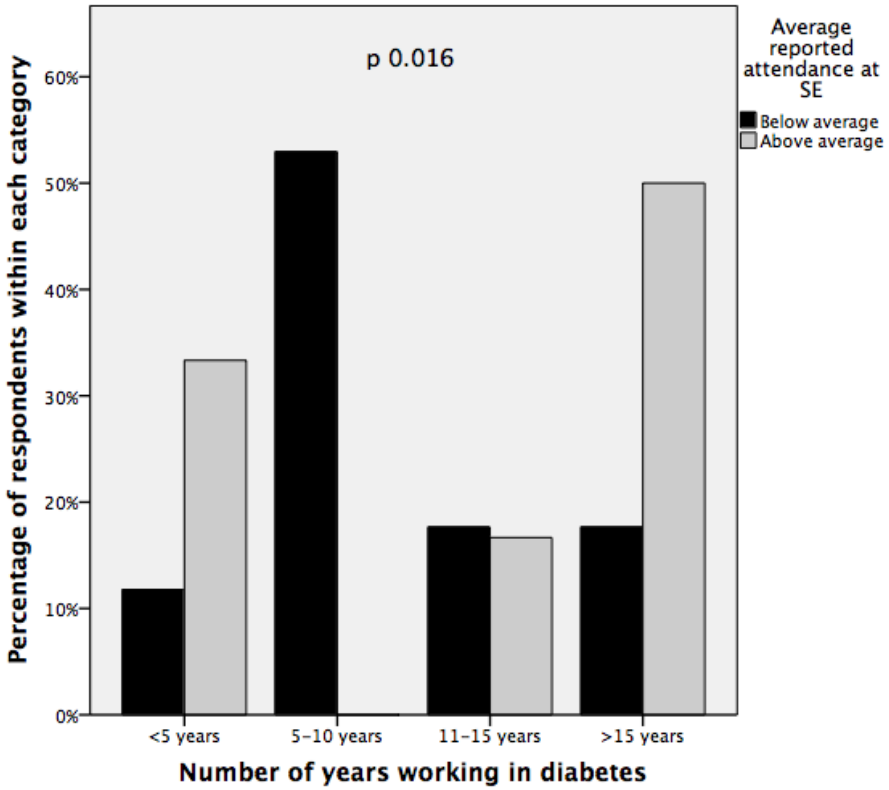
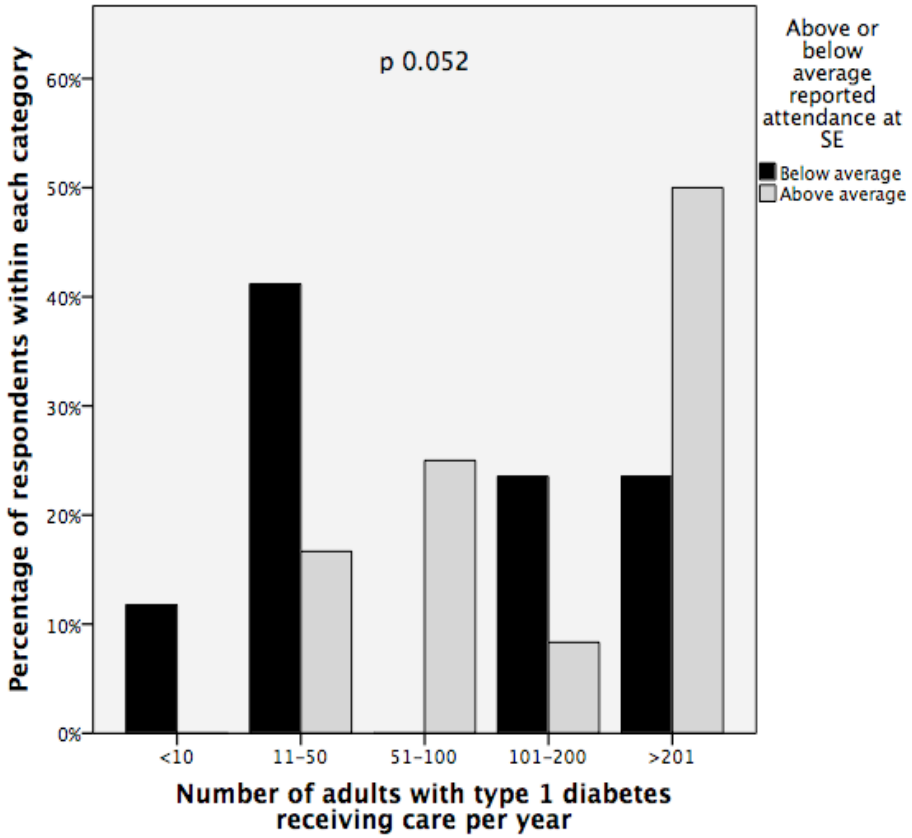


Figure 13-4 illustrates a clear trend, although not statistically significant (p=0.05); respondents caring for many patients with T1DM report an above average attendance rate. This corroborates the difference seen between specialists and primary care providers. As number of years' experience influences attendance, so too does job title, with Consultants, DNS and Psychologist reporting above average attendance. Dietitians report a below average (or maybe realistic) attendance rates, as do Speciality Trainees. GPs report below average attendance, and this is likely due to them serving the wider community dominated by T2DM, and including those not attending specialist care for their T1DM thus not qualifying to attend DAFNE due to the existing referral pathway. These two pieces of

information illustrate that self-reported attendance at DAFNE is better for specialist services, serving a larger T1DM population.

Figure 13-4: Bar chart illustrating percentage of respondents with above or below average reported attendance at DAFNE according to number of people with type 1 diabetes attending their clinic annually. Statistical significance taken as <0.05.



13.2.4 Analysis according to observation of DAFNE course

Almost 40% of HCPs felt better marketing would lead to greater attendance rate. There has been anecdotal evidence that HCP observation of a SE course makes them better able to discuss the course with their patients, improving attendance (Pender, 2016, All Party Parliamentary Group on Diabetes, 2015), as well as providing skills to conduct a clinic consultation with DAFNE graduates and not feel overwhelmed by the 'expert' patient (Snow et al., 2013). There is currently no published evidence for the impact of observing or attending a DAFNE course on the HCP or their patients. Given the strong influence that HCP messaging played on attendance in P2 Sample B analysis (Table 11-12), I carried out further analysis to investigate whether DAFNE observation would be a suitable recommendation to increase patient attendance in the future. Responses were analysed according to observation of DAFNE course or not.

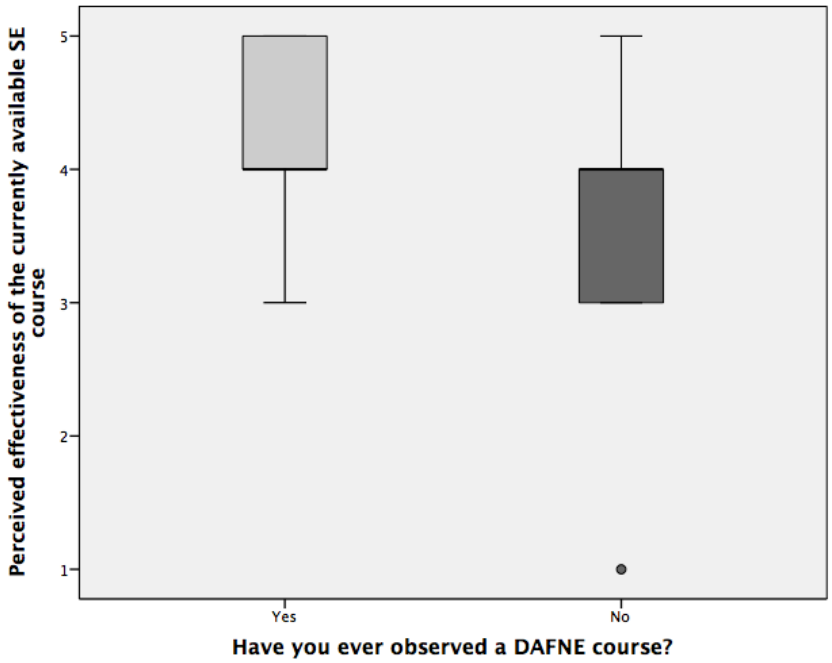
*Table 13-5: Univariate analysis comparing respondents who have observed DAFNE versus those who have not. Categorical data shown as count and percentage (%). Continuous variables shown as median and inter-quartile range (IQR). Statistical significance taken as p <0.05. * score for importance of self-management was constant with having observed a DAFNE course*

Variable	All respondents	Observed DAFNE	Not Observed	p value
People with T1DM are capable of self-management n29	5 (4-5) 4.5 +/- 0.1	5 (4-5) 4.5 +/- 0.1	4.5 (4-5) 4.5 +/- 0.2	1.0
How important do you think self-management is for your type 1 diabetic patients? (0-5) n 56	5 (5-5) 5 +/-0.1	5 (5-5*) 5 +/- 0	5 (5-5) 4.9 +/-0.2	0.15
How effective do you feel current structured education programmes are at facilitating patient self-management? (0-5) n 56	4 (4-4.75) 4.1 +/-0.7	4 (4-5) 4.2 +/- 0.6	4 (3-4) 3.8 +/-0.9	0.05
DAS-3 percent n29	83% (78-82)	80 (77.5-85)	85 (81.9-91.9)	0.06
DAS-3 patient autonomy sub-scale	84 (78-90)	84 (76-88)	94 (88-100)	0.001
What the patient does has more effect on the outcome of diabetes care than anything HCP does.	4 (3-4.5)	4 (3-4)	5 (3.8-5)	0.031
People with diabetes have a right to decide how hard they will work to control their blood sugar	4 (4-5)	4 (4-4)	5 (4.8-5)	0.004
People with diabetes have the right not to take good care of their diabetes	4 (3-4)	4 (3-4)	5 (4.8-5)	0.001
The important decisions regarding daily diabetes care should be made by the person with diabetes	5 (4-5)	5 (4-5)	4.5 (4-5)	0.94
Healthcare professionals should help people with diabetes make informed choices about their care plans	5 (5-5)	5 (5-5)	5 (4.8-5)	0.77
Number in clinic (n29) Completed SE	5 (3.8-6.5), 5.03 +/-2	5 (4-7)	2.5 (1.8-5.5)	0.041
On waiting list	1 (1-2), 1.5 +/- 0.87	1 (1-2)	1.5 (1-2)	0.89
Referred but didn't attend	1 (1-2), 1.6 +/- 1.27	1 (1-2)	2 (0.8-2.3)	0.51
Declined referral	1 (1-2), 1.6 +/- 1.47	1 (1-2)	2 (1-4.5)	0.17
Not been invited	0 (0-1), 0.54 +/-0.92	0 (0-1)	1 (0-1.5)	0.32

Table 13-5 illustrates the analysis of variables according to respondents' prior experience of DAFNE. There was no statistical difference between the scores given for the question 'How important is self-management for you patients with type 1 diabetes?'. This question was non-discriminating and is

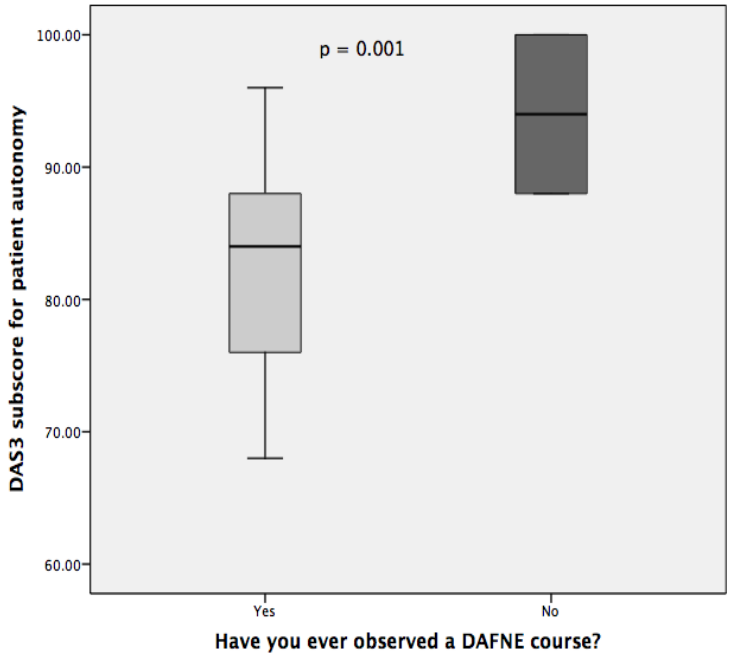
therefore a redundant question, likely due to response bias. It would be hard not to score the importance of self-management positively when NHS England recommend that "supporting patients to be actively involved in their own care, treatment and support can improve outcomes and experience for patients, and potentially yield efficiency savings for the system through more personalised commissioning and supporting people to stay well and manage their own conditions better" (NHS England, 2016b). A statistically significance difference was found between respondents' beliefs that the currently available course is effective in providing skills to enable self-management (see Figure 13-2). Although response bias might be expected to make this question equally weak, those who have not observed DAFNE feel less strongly about its ability to prepare people to self-care. $p = 0.05$

Figure 13-5: Box and whisker plot of perceived effectiveness of the currently available structured education courses according to previous observation of DAFNE course.
The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the results. Statistical significance taken as p <0.05.



There was no difference in the overall DAS score between the two groups, however the patient autonomy subscale found those who had not observed DAFNE felt more strongly about patient autonomy (p=0.001) (Figure 13-6). Each individual question making up the subscale was analysed and are shown in Table 13-5. Those questions pertaining to an individual's choice as to how hard they work to maintain diabetes control were the ones showing statistically significant difference in scores. Most respondents who had observed DAFNE were working in secondary or tertiary care (23% primary care vs 82% secondary & 79% tertiary care, p=0.001), and may be more aware of consequences and economic burden of complete autonomy.

Figure 13-6: Box and whisker plot showing the relationship between the respondent's DAS score and subscale according to previous observation of DAFNE course.
The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the results. Statistical significance taken as p <0.05.

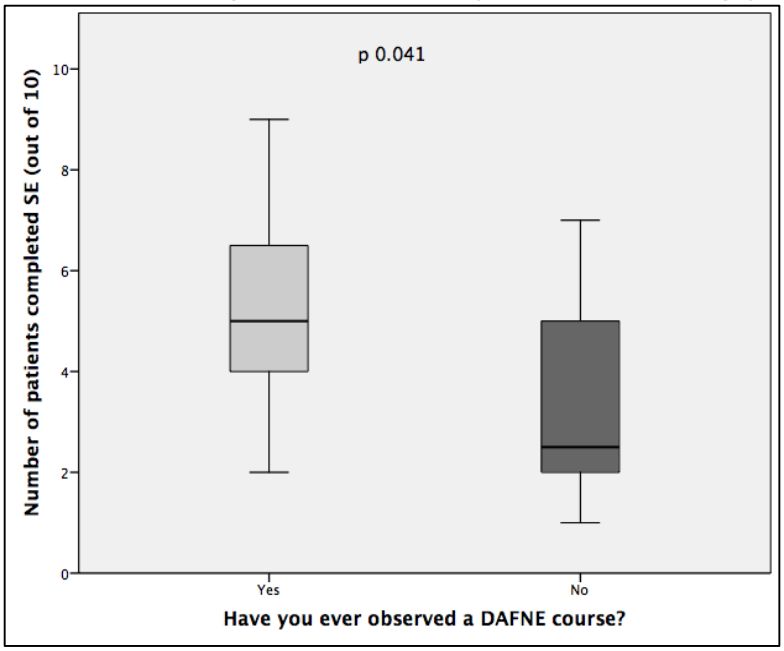


Lastly, healthcare professionals were asked to estimate the number (out of ten) of their patients in the five different categories, from attended SE to never discussed SE with them. The only difference was seen in the number who have attended DAFNE (

4231 Figure 13-7), with those who had observed DAFNE judging that half of their clinic have attended
4232 DAFNE (5 vs 2.5, p=0.041).

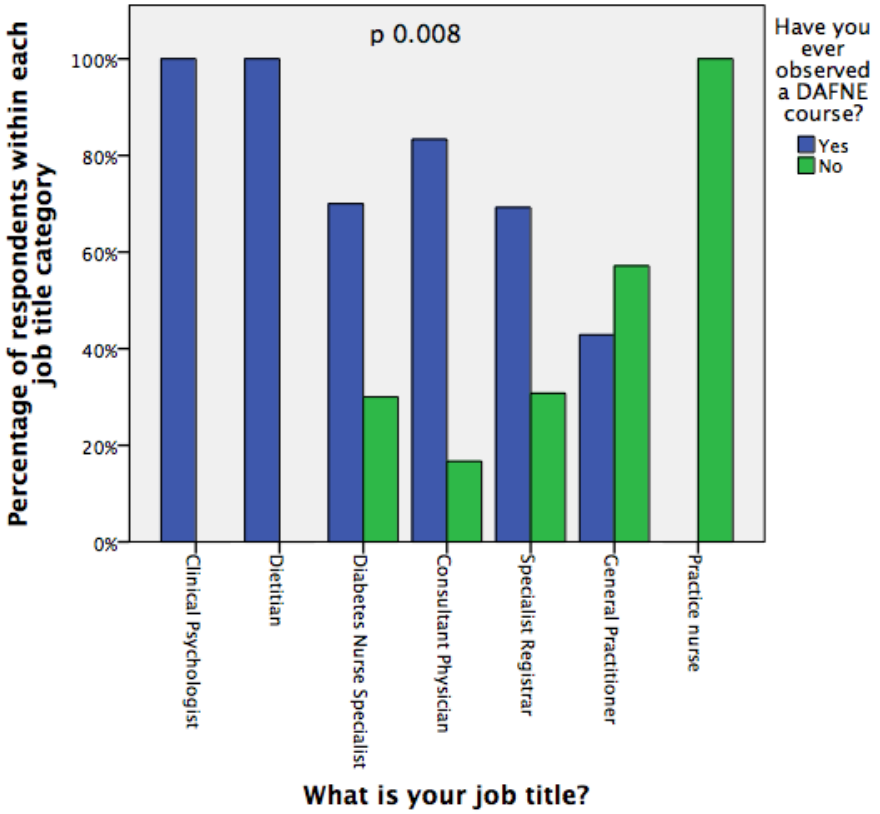
4233

Figure 13-7: Box and whisker plots illustrating number of people (out of ten) within each respondents diabetes clinic who has completed SE according to previous observation of DAFNE course.
The horizontal line within the box indicates the median, boundaries of the box indicate the 25th and 75th percentile and the whiskers indicate the highest and lowest values of the results. Statistical significance taken as p <0.05.



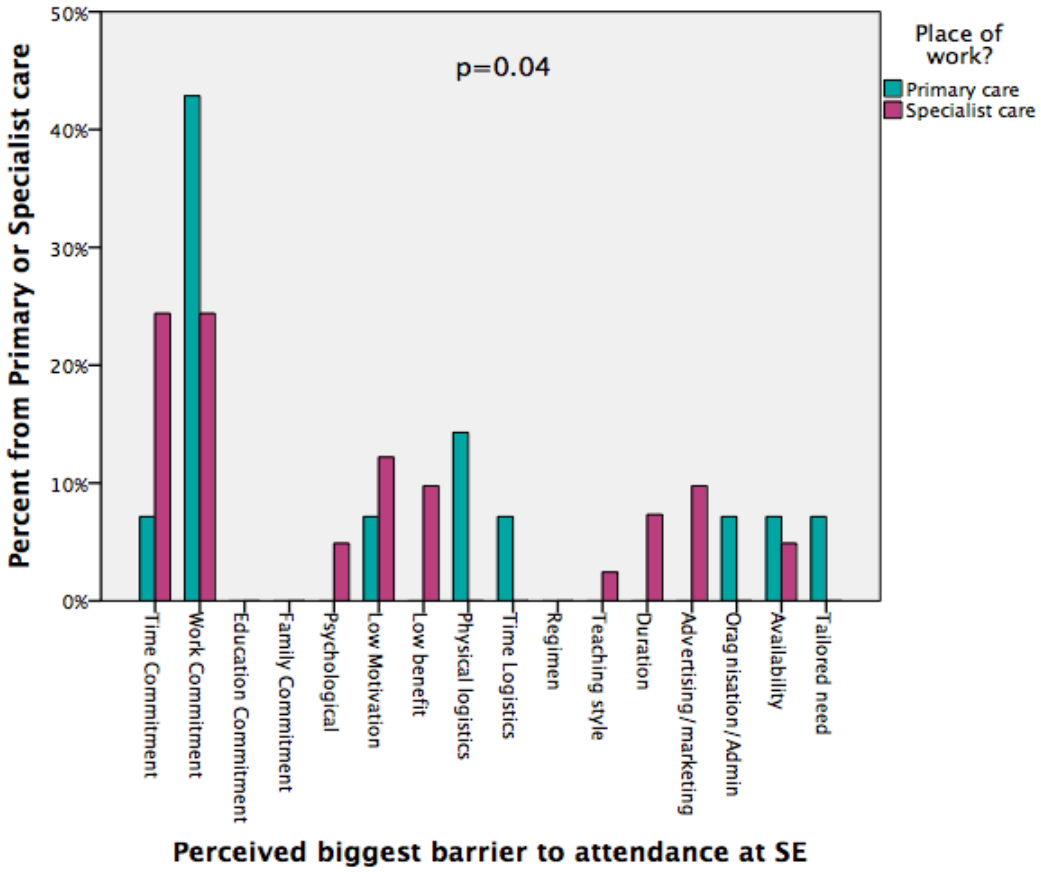
Respondents who had not observed DAFNE appeared to look after fewer people with T1DM per year although this was not statistically significant. There was no difference in reported ability to recognise health literacy or prescribe accordingly. However, there was a difference in job title and place of work; with less than one third of those in primary care having observed DAFNE versus more than three quarters of those in secondary and tertiary care (p=0.001).

Figure 13-8: Graph showing the percentage of respondents within each job title category who have observed DAFNE. Statistical significance taken as p<0.05.



The difference between respondents observing DAFNE according to job title is shown in Figure 13-8. Of note, no Practice Nurses had observed DAFNE whilst almost half of GPs, and most Specialty trainees, Consultants, DSNs and all psychologists and dietitians had observed DAFNE (p=0.008). Given that respondents were invited only if they looked after people with T1DM, and for those offering specialist care they are working in a geographical area steeped in DAFNE culture I am surprised that almost a third have not observed DAFNE. A similar distribution and significance was seen for diabetes-specific qualifications (p=0.006), although it is worth noting that 100% of people who had completed a PhD or MD had observed DAFNE, despite this being discounted as diabetes-specific qualification in the analysis above (Table 13-1).

Figure 13-9: Bar chart illustrating the different barriers to attendance identified across primary and secondary care respondents.
Percentage of respondents from primary or secondary care identifying each barrier is shown. Statistical significance is taken as p<0.05.



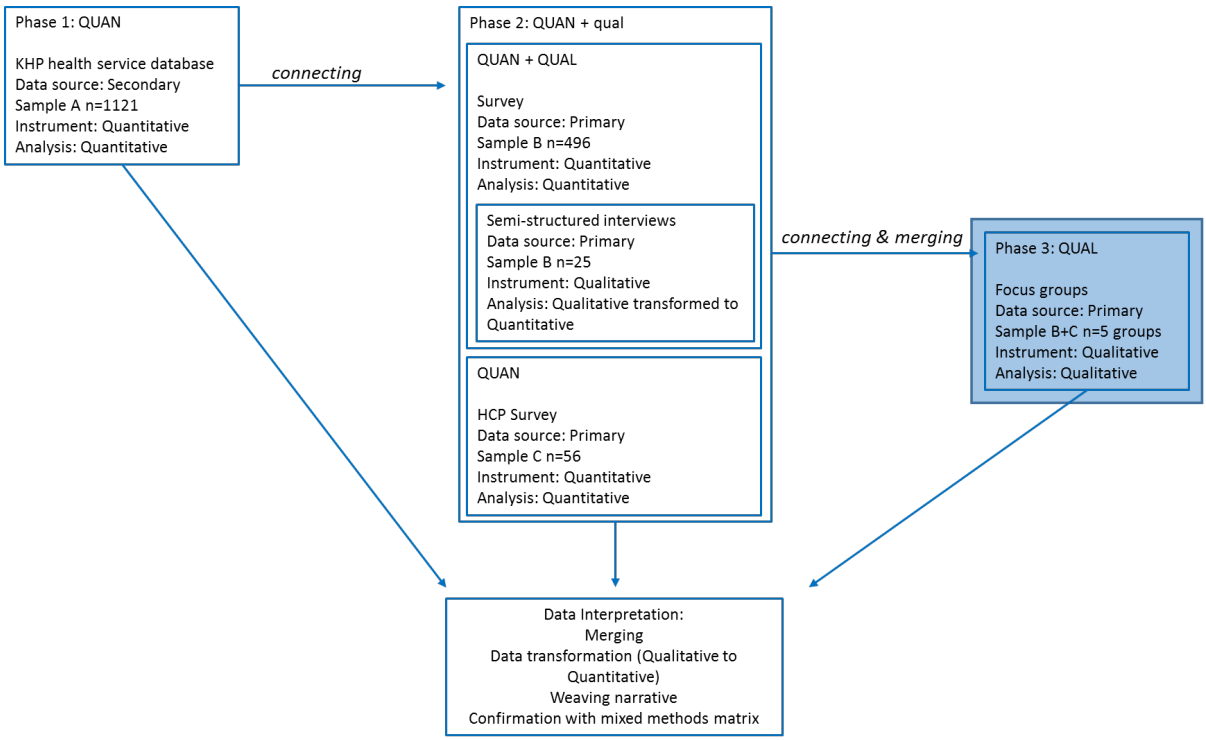
This graph shows that there are certain barriers not considered by either primary or secondary care HCPs, for example marketing and duration are seen as barriers by specialist care healthcare professionals, whereas primary care sees physical and time logistics as barriers. This may suggest that each group is in contact with a different group of patients, with different needs. In order to encourage attendance of the 20% who do not attend specialist care there needs to be involvement of primary care colleagues as there are certain barriers that would not be addressed without their (and their patients') perspective.

13.3 Key Points & Discussion

HCP response to this survey was poor, meaning that Sample C was underpowered to answer many of the questions regarding factors influencing attendance at DAFNE. Additionally, there is likely to be a selection bias; indicated by respondents scoring higher in the DAS than the validation of the scale, where mean total was 78.2% and score for patient autonomy slightly lower at 75.6% (converted from validation paper where scores shown on 0-5 scale (Anderson et al., 1998)). This along with the response to the question about importance of self-management and the high overall belief that DAFNE is effective at delivering skills for self-management, suggest a response bias. However, the key points taken forward into P3 are:

- There was a broad spread of responses from healthcare professionals across South England
- The overall response rate was disappointing and meant there was generally insufficient power to draw wide inferences
- There was overestimation of attendance rates at DAFNE
- Respondents who reported above average attendance rates:
    - were working within Specialist care
    - had more years' experience
    - appeared to care for a larger T1DM population (although not statistically significant)
- Respondents who had observed a DAFNE course reported:
    - Higher attendance rates
    - Greater belief in the ability of DAFNE to transfer skills for self-management
    - Lower belief in patient autonomy
- Most respondents felt able to recognise low health literacy, and adapt their treatments accordingly.
- Primary care and Specialist care HCPs perceived different barriers to attendance.

14 Phase 3: Focus groups



14.1 Methods

As outlined in the methods chapter, phase 3 used participatory research to sense check early findings from phase 1 and 2, but predominantly to discover potential solutions to identified barriers and further explore these. Focus groups allow this dialogue to occur with little prompting from the researcher, and this was my main reasons for choosing this method (7.5.1.2). The focus groups involved people from both Sample B and C (people with diabetes (PWDs) and HCPs) as well as experts in the field. This broad group of people provided a breadth of understanding and potential solutions, bringing different backgrounds and experience to the focus group discussion.

Two different focus groups were carried out. The topic guides for these focus groups were determined by the preliminary results from P1 and P2. The key findings from both phases were integrated to produce a background for the topic guide. These were reviewed by the study advisory group prior to use.

One of the focus groups covered the general findings of P1 and P2, and allowed free discussion of the potential solutions, to explore a broad range of ideas. The second focus group was specifically tasked with discussing potential digital solutions, such as online and modular education as well as

access to online resources, as this had been one of the potential solutions discussed by many of the interviewees in the P2 qualitative research study. Additionally, there has been much attention on digital solutions for SE over recent years, as a means to provide SE at scale (Bolin et al., 2013, Blanson Henkemans et al., 2013, Murray et al., 2015).

Three used the general topic guide, and had participants from across the SE pathway including a public health consultant, commissioner, provider and people with T1DM, both those who had and had not attended DAFNE. Some attendees had multiple roles, for example PWD, involved with both third sector and education providers. These people were analysed according to the role that they were originally invited, as often the multiplicity of their roles only came to light during the focus groups. Two focus groups specifically discussed digital solutions, although the conversational flow of one was broader and included many topics unrelated to digital solutions. These two focus groups were made up of people with T1DM only, from a broad demographic range.

14.2 Results

In total 28 people participated in five focus groups, ranging from nine to three attendees in each group. The mixture of backgrounds is shown in Table 14-1 . Individual's data are presented below using PWD (person with T1DM); ND (non-DAFNE) and D (DAFNE) and HCP to identify who is talking.

Table 14-1: Table of focus group participants, illustrating the mixture of professions, experiences and demographic backgrounds represented.

NHS employees		**People with diabetes (PWD)**	
Characteristic	Number	Characteristic	Number
Job title: • Dietitian • Diabetes Specialist Nurse • Diabetologist • Public Health Consultant • Commissioner	 3 3 1 1 1	DAFNE attender? • Yes • No	 9 10
		Gender: • Male • Female	 14 5
		Ethnicity: • White • Non-white	 14 5
Southwark/Lambeth based? • Yes • No	 5 5	Age group: • Young (18-30 y/o) • Mid (30-50 y/o) • Older (>50 y/o)	 5 8 6

The transcripts from these focus groups were analysed using thematic analysis, as described in 7.5.2. The initial themes identified are shown in Table 14-2.

Table 14-2: Table illustrating the different codes used in the original qualitative analysis of the focus groups and the emerging themes taken from these original codes.

Original NVivo codes	Emerging themes
Current innovation	recoded into the below
Potential innovation	recoded into the below
Alternative media: **Social media** **Website**	Alternatives
Delivery method	
Marketing	Marketing DAFNE
Peers	
HCP influence	
Motivators	Supporting individuals
Psychological support	
Overcoming literacy or numeracy	
Logistics	Organisation/Logistics
Commissioning and financing	
Pathway	
Perceived barriers • **age** • **culture** • **educational difficulties** • **employment** • **gender differences** • **service use** • **other**	Barriers
Psychological	
Perceived low benefit	
Time commitment	
Work commitment	

Exploration of the barriers to attendance at SE for adults with T1DM is a complex problem which has required examination of the entire SE pathway, from commissioning the service, through to motivation for attendance. This called for a broad mixture of both HCPs and PWDs to be involved in the focus group work. Table 14-2 illustrates the emerging themes for improvement to enable greater access. These mirror the breadth of experience brought by everyone to the focus groups; as the themes spread from organisation and financing courses to supporting individuals to attend. I report

these results using the SE pathway, shown in Figure 14-1, demonstrating potential points at which improvements could influence greater attendance.

Figure 14-1: A simplified diagram of the SE pathway from commissioner to person with T1DM

14.2.1 Organisation or Logistics

There is a need **to increase capacity** to maintain motivation and provide for all those eligible.

> *"…don't have probably enough courses running in the year… by the time we get round to ask them, that enthusiasm's fallen off a little bit, because it has taken a bit of time to get round to top of the list... we don't have the staff anywhere close at the moment." HCP*

> *"they're up for it, and they'll do it next week, but then, give them that little gap, and it's forgotten, and something else has got in the way, you know?" HCP*

However, some healthcare professionals wondered if the waiting list makes it more appealing.

> *"If there's a bit of a waiting list sometimes it makes the programme appear more desirable." HCP*

Others suggested that being **aware of the cost** would encourage attendance.

> *"But what would be nice is to see someone wants to spend £700…" ND PWD*

People with diabetes wanted to be able to book the course for themselves, with a digitalised platform allowing them to choose the date and venue that suited them.

> *"…have DAFNE online as a set of, of things, that people can just go, 'Yeah, I want to go to that DAFNE course'... Yeah, you have to be referred or invited. How about you just put a schedule up and then fill it up?" ND PWD*

Such autonomy would allow PWD to overcome administrative barriers to attending.

> *"I've been booked on last minute twice, as if I'd been slotted in, and I do work, I have a family, and I, I have a whole life to run… but their admin and planning…it's not worked out, and I've been asking for years." ND PWD*

"I had to be really proactive about it, like I had, like, get the list of the dates, and be, like, 'This is the one I want to do', and I had to, like, ring up and make sure I, kind of, got that one, and line it up with work then." D PWD

Access to self-booking would allow PWD to cross commissioning boundaries to receive their diabetes education. One HCP, who also works in commissioning, felt that **people would then drive improvement** if given the option to receive their education out of area.

"It is about patient choice… where you as a, as a patient get a good offering, I think that's really good… so if Service Y isn't providing a good service, well then they need to buck up, don't they, and improve it?" HCP

However, it was recognised that structures would need to be in place for the patient to **return to their normal care provider.**

"…you've got to be careful that when your service's elsewhere, if they then want to come back locally, and the people locally are not trained to support them." HCP

"…if, when you'd run the DAFNE course, and there wasn't DAFNE-trained people…in the clinic…to hand over to, then it's virtually impossible." HCP

One PWD questioned whether he would have completed the course if not organised by HCPs that he knew and felt obligated to

"let's say I had gone to a different hospital…where I'm completely anonymous… and I've got no emotional contract…whether I would have stuck it out" D PWD

others were concerned about the risk of **mixed messages.**

"So, I think it's not only mixed messages, I think there's just, there's just gaps everywhere. You can change from X [hospital] to Y, it's different again." HCP

An additional advantage of **centralising DAFNE booking** would improve the administration associated with it, as this could also be shared.

"we book nine people on the course, running for eight people…we definitely had somebody dropping out, so there's a lot more admin…there's a lot more commitment with admin needed nowadays than we used to have…" HCP

Those involved in administration would be knowledgeable and **skilled in preparing** individuals for the course.

"we'd call the patient and go through it, and… we always do the expectations of certain thing… sharing your diary… then you'd have it again at the pre-assessment" HCP

It could also allow data recording so that all referrals could be captured, and **non-attenders offered alternatives**.

"We are keeping a record of that [DNA], so we will offer them a subsequent course, umm, negotiate when they would like to come" HCP

But data sources are poor

"we were trying to identify our Type 1 population, almost nobody could say..." HCP

and south London poses individual problems, as one HCP found when trying to create a local database.

"…we've got a very transient population, so people come and go, and then we lose tabs on people…" HCP

This problem could be overcome by improving the linking of primary and specialist care data systems.

"I think the only way you do that, is that all NHS, umm, patient information systems need to talk to each other (laughter)." HCP

"The NHS just kind of seems like it's fragmented-," D PWD

14.2.2 Alternative courses or format

Recent changes to DAFNE, and other SE courses to allow people to attend over **one day per week** has provided choice and flexibility

"we found it useful having the five day a week and the one day a week, because it gave people an option…" HCP

"more appealing in that it wasn't five days, which meant that it was a bit more flexible work-wise." D PWD

"…for people with young children…getting someone to look after your child one day a week for five weeks is easier than finding someone five days in a row… people who are self-employed, there might be a one day a week they could take…" HCP

but the HCPs report that there appears to be a disconnect in the realisation that the course is still five days long.

"…we're now able to offer the five week course, a day a week for five weeks… then people realise it's actually a five week commitment…" HCP

Questions remain; as to what the **optimum course duration** would be

"…there was another one that I was offered that was…one day…across…four or five months or something…I felt like that was too much… if you do it over a five month period, it's too long…" D PWD

"even the two days a week, it may be too much… maybe to do either an evening course, or maybe an, a weekend course… then it might fit, flexibility for other people's lives..." D PWD

"…only when you do take time out…that you actually stop to address it. Now, whether that just needs a two-minute conversation as part of the consultation, or whether it's an online learning thing and you can mention it next time, or whether you need to take a week off, I, I honestly don't know." D PWD

and **when the courses should be held**, with PWDs recognising that their HCPs may not choose to work weekends.

"Unfortunately, the people educating you…don't work on the weekends either." ND PWD

HCPs reported poor attendance when they offered this option.

"it [weekend refresher day] was the least well attended. Because again, I think people have other things they want to do on the weekend, don't they?" HCP

Another alternative suggested was to offer a **modular course** made up of core themes.

"…you need to have within the modular aspect, you need to have a core theme that everybody would need to do…in order to meet the minimum criteria…" D PWD

Modules would be built around providing education at the point at which the individual needed it, in order to maximise their experiential learning.

"…the needs of the people as they develop…" HCP

"…even if you're taught something like that [sick day rules] …the chances are you may never use it…and you're not refreshing yourself on it." D PWD

The modules would use the **tools created by DAFNE**.

"… it would be nice if we could use those tools [from DAFNE] …I do; I use the sick-day rules…" HCP

The modular learning may allow some people to **move faster** through the material

"I really don't think it needs to be five days, though. And that might be why people drop out" D PWD

or more slowly, depending on their **learning needs and ability**

"…something they can dip in and dip out of, and maybe take longer than that five days." HCP

"It depends on how quickly you take on information, how quickly you can start applying these things, and how quickly you then go… everyone's different on that basis…" D PWD

"…maybe the five days is not…not sure how you phrase it, but people who are, you know, not good at maths…" D PWD

It was recognised that organising the provision of modular learning in a way that met the quality standards would be difficult.

"…I think a modular approach is good, because people need sick-day rules at a certain point, and that's when are they going to remember them… How do you capture that that person has done that one module, and they've got three more to do before they've got their structured education" HCP

Many people recognised a gap in the market between **day of diagnosis** and eventual offer or attendance at DAFNE.

"So I would have preferred to have done, to be able to do DAFNE straight away." ND PWD

"I can remember the shock…very clearly…if someone had said to me then, 'okay…here's a course, this might help you', I'd have probably…be pretty open to it…because I'd have nothing to lose" NA PWD

"…we're talking about having some access to offer it [early diagnosis course], because… that's when you've got all the questions, isn't it?" HCP

However there was also recognition that DAFNE itself might be inappropriate at early diagnosis

"…between diagnosis and, and DAFNE…it would need to be very different material…you couldn't just hit people with the DAFNE material straight away, because they would just get lost."

"…something that would allow people to not be getting inconsistent, mixed messages…You don't need the full, structured five days…but you need some basic

and that **systematic integration of education** into diabetes care could increase attendance.

"you've got a structured process of how you actually engage people, and get them through wherever, to that point, where they actually are on the course… so if you haven't got a system, you can't get the throughput." HCP

"…then that's going to be my pathway, so in six months' time I know I'm moving from here to there." ND PWD

"If you got a letter saying, 'Your DAFNE course is booked, you will be going in a year's time, here are the dates'… the uptake would increase, because a little bit like your clinic appointment, it's already booked there for you, and it's much harder to reject something that you're signed up to." ND PWD

However, offerings would need to have sufficient **flexibility** to allow people to attend at different stages in their diabetes as and when ready for it.

"…people's attitude to education changes, people's attitude to going to groups changes as the years go by, don't they?" HCP

Some PWDs suggested that clinic appointments should be utilised as an opportunity to educate.

"…if they are already there, why not give them the information… You're already at the hospital… for an appointment time of three hours, maybe, say you might be there for five hours." ND PWD

This embedding of education within clinic visits with a clear pathway would need to start from an early age with **parental/guardian education** for those diagnosed as children

"…parental buy-in… to get them started early…but you actually have to sell the value…it's a family thing isn't it? It's a whole, holistic, got to get everyone in there…" HCP

and recognise the importance of **educating partners**, with many people wanting to bring their partners on the course

"But my girlfriend would have…she would have went to the whole, for the whole thing…it's part of our lives, like it's part of both of our lives, so it would have been good if she was able to go the whole thing." D PWD

"I know from my girlfriend… it was nice for her to speak to…partners of people who've got diabetes" D PWD

"I might bring her with me…" ND PWD

There may be value of providing more culturally sensitive courses with focus on the communities' needs.

"I think that the peer support…and the unisexual approach…would be a winner there [within s. Asian community]." HCP

The difficulties of providing courses in different languages were recognised.

"Language barriers, we, we just haven't got the resources for that." HCP

Although courses where cultures and age groups are mixed appear to be well received, by adding another discussion point to the course, this came from individuals who have already agreed to attend and overcome the potential cultural barriers discussed above.

"…culturally as well as age, because…the topics of discussion around different foods and things…feedback's been quite positive about a mixed setup. I also appreciate the value, for some people…that might be their preference…" HCP

The power of social media was recognised

"I follow, like, my DAFNE cohort on Twitter, and sometimes they'll tweet about stuff, and that will prompt me to have one day when I feel particularly motivated…" D PWD

and had been harnessed by some HCPs.

"…our department set up a Twitter account… and we do do educational things through Twitter" HCP

However, one HCP was concerned about recommending social media and blogs to PWDs.

"…using social media, and different things for sharing experiences, but if there was some sort of…place that you knew was very safe… trusted, reliable…point them in that direction." HCP

Participants questioned whether there were elements of DAFNE that could be done online.

> *"Is there some of the content of DAFNE that you could move online, and then do…a four day… or just like even an hour meeting, just for the more collaborative, let's call them, parts." D PWD*

However, it was appreciated that moving SE online would be a vast piece of work

> *"It sounds like a great idea to have a different course to DAFNE. It just sounds like such a task… somebody needs to do this (laughter)." HCP*

but may capture the younger generation

> *"Because the cohort of people that you're trying to get, is generally going to be IT-savvy, nowadays. So actually, learning in different fora is actually better for them." HCP*

and would need a culture change for the older generation, who were diagnosed prior to the internet.

> *"…if you've grown up with it, I think you have a different perspective… grew up with it, there wasn't an internet." ND PWD*

The benefits seen from providing digital SE was seen to allow people to access it in their own time

> *"…I just went and did BDEC, because it was something I could do in my spare time, at my own pace, which is the difference between that and doing DAFNE.' ND PWD*

and move through the content at their own-pace.

> *"…like self-paced learning online… a dedicated website or something like that would be great." D PWD*

> *"You've got a health professional, you've got a-, twelve other diabetics there…another diabetic health professional... on Skype, 8 till 9, done. The next session will happen, maybe two days later, or the next day." ND PWD*

Participants had ideas as to what they would like from a digital SE solution, including a facility to **upload and share their data**

> *"…something where the person can, sort of, upload their data…" HCP*

as well as offering support via **a forum.**

'…it [forum] should be on a national level, because then you have the forums that people can go online and discuss issues…Everyone could help one another, and maybe people who are, who are alone, they'd go online." D PWD

However, based on experience of other diabetes forums;

"…the forum responses [on a particular website] are not particularly moderated, which means that anybody can literally tell you anything on it." ND PWD

"I think, think that peer-to-peer thing is something that we don't do very well at the moment…because the main thrust of it [online community] is people talking to each other… the difficulty is the, kind of, how do you rate the advice you are getting?" ND PWD

"I find some of the online communities a bit of a nightmare…a bunch of people with attitude…who are pushing certain agendas... I find it's a bit of a turn off…when you do look around… you can end up anywhere really quickly." D PWD

it would require **moderation** to reduce risk of mixed messages.

"I think forums can be a bit dangerous, though, because, like, people posting on forums are not medical practitioners." Both D PWD

"…it's the moderation…that's important." D PWD

Some ideas to help with moderation included asking people to sign in to comment

"…you need to have it [website] open so people can go and look at stuff, but if people have sign up to the forum…" D PWD

as well as the ability of participants to vote or rate comments.

"…this is where the votes would come in handy, and downvotes, if some random person is… churning out stupid advice, trying to cause trouble… it would never make it there, or get downvoted." D PWD

Others felt there needed to be clearer moderation that would be done **by both HCPs and PWDs**

"I think you need both [HCP and PWD] on there because you're right, it's nice to see, to talk to other diabetics, and their experiences or tips and stuff, but if there's something really, a medical question, I'd rather hear that from a professional… I think you need a mixture of both, definitely." D PWD

with a clear set of rules and boundaries.

"You just need to set the rules and standards to make it very clear that there is no-one [moderating the forum] between x time and this time." D PWD

Some would like to see information being more readily available online, in one place.

"if… there's an app. I have to sign in, and everybody's signed in to that app, and it says, 'So-and-so is online, have a chat…If I could go to somewhere for practical information, food information, exercise information, whatever, if that app had it all, then that would make it a lot more easier for me…" ND PWD

One participant involved in a large diabetes forum, described the recurrence of certain questions online, and that information could be tailored to answer these questions.

"So they've got a vast collection of data of commonly-asked questions, that are… repeatedly being asked, and …basically dishing out the same answers, because they are the same answers." ND PWD

Although digital solutions were widely accepted by most participants, some felt digital was not the solution for education, PWD and HCPs included.

"What channel to…stream people towards? I.e. if you need it purely for practical information, then sure reading it online is fine. If you're looking to be motivated… because you feel a bit low…is that really the proper channel?" D PWD

"I love the idea of, like, doing it face-to-face, as opposed to over the internet, personally." ND PWD

"…if I was sat online at home doing it, would I actually have taken it on board? Nah." D PWD

"I would find it really difficult, being on the other side as an educator, doing the online, because you ask so many questions around somebody's diary to actually get the full picture…maybe, starting something face-to-face and then carrying on online…" HCP

14.2.3 Marketing

Most participants, interested or not in digital solutions, found the marketing of DAFNE was a big issue.

"Marketing's complete rubbish…it doesn't matter where you do it, if you don't explain what it is, then I'm not interested. I spent eighteen years, going 'I'm not going on it'." D PWD

The healthcare professionals were felt to not be giving enough weight to the conversation around SE, often assuming prior knowledge.

> *"There was an assumption from the healthcare professional…no-one actually took the time to explain, 'Well, this is what it is, this is how it can benefit you'…" D PWD*

> *"Yeah, I'd, I'd agree with that, so that any explanation was, kind of, it was very condensed…kind of, tacked on to the general conversation…" ND PWD*

The HCPs felt that it was important for care providers to understand the DAFNE curriculum to market the course to their patients.

> *"I think the misconceptions come from the registrars sometimes, how they sell the course, because they're not all DAFNE-aware…" HCP*

> *"…we have six consultants…and three of them are now DAFNE-trained, so they speak the language." HCP*

Some HCPs had provided local training to ensure their team could discuss DAFNE.

> *"…we've done training on all our nurses and dietitians to make sure they've got the message. The consultants didn't come to that…as nurses and dietitians, we're probably all giving the same information." HCP*

Whilst others felt that HCPs needed to observe the course to sell it better.

> *"…if you've been through it, you're better at selling it…" HCP*

Participants recognised the role their HCP played influencing their attendance

> *"It must make some difference, mustn't it? That if you've built up some sort of relationship with that particular healthcare professional over time, that's going to be different than seeing a different doctor every time you come, or whatever?" HCP*

but that this was resource intensive

> *"… [HCPs engaging with individuals] that requires time, patience, and manpower…" ND PWD*

So, some suggested that PWD who have completed DAFNE would be better placed to discuss the course

"Well, your best marketeers are probably going to be people who've done it..." D PWD

"…and one of the patients said exactly that, you know, 'I need to come and meet the people before they go on DAFNE, so that I can tell them how good it is'." HCP

especially given that people who had completed the course described very different 'selling points' to the course.

"Meeting other people…with the same condition as you…it's nice to know that you're not on your own" D PWD

"For me, it was about taking control, and being empowered…and also being able to argue back… by having that structured education, you actually feel '…Let me get on with it, and that's my job'. D PWD

So, improved marketing would need to enable the benefits of DAFNE to be marketed to individuals according to their needs.

"…so not only is it not explained as to what it is, but there's little if any contextual reference to why is it relevant to me?" D PWD

"…it is a bespoke course, isn't it? …it's not a general thing that you can tell them about, you need to be able to…make sure it's…right for them, and be enthusiastic." HCP

Such concepts may be better portrayed by a peer, than HCP.

"I think the difference is the personal element, we see it as outcomes …relate it to the patients… 'I was too scared to exercise… I went on DAFNE… now I go to the gym and I don't have a hypo'." HCP

"…if you've been through it, you're better at selling it, because you see the benefits of it, whereas …the doctors say, 'This is a course you have to go on, and the guidelines are, you know, you should'…" HCP

One of the issues around peer marketing is the isolation associated with having T1DM

"I found it interesting that after about twenty years… met my first other Type 1 diabetic…" D PWD

and the way that diabetes clinics are set up are not conducive of conversation.

"…getting your DAFNE graduates to talk to the people who aren't going anywhere near it… it comes back to the isolation of Type 1... Nobody at clinics ever talked about who DAFNE graduates were, and no DAFNE graduates would ever stand up in a clinic and say, 'By the way, I did DAFNE and it was great.'." ND PWD

"I always want to [start conversation], but I'm scared they'll just think I'm weird." And "Maybe a coffee, coffee machine…" both ND PWD

There may be benefit in recruitment events, as some Trusts do, purposely bringing together DAFNE graduates and those considering attending the course.

"…recruitment evenings, where we invite speakers, patients that have been through DAFNE…speaking to other patients, it's been their testimony that has persuaded them to, to go, rather than us telling them…" HCP

Alternative methods of recruitment were suggested, such as utilising primary care colleagues.

"I don't think we should really overlook the GP services maybe having a DAFNE ambassador…somebody that can signpost and… actively promote, with a happy face; what's going on out there, with dates and times." ND PWD

Whilst others thought that leaflets should be sent to all people registered with T1DM, and the local retinal screening team could be used to ensure this was done systematically.

"…you could tie it [leaflets/marketing] in with things like retinal screening…" HCP

Others felt that leaflets would not be read, or captivate people.

"…the leaflets you get…I ended up getting so many leaflets from my GP and from the clinic as well…I haven't read half this stuff…" D PWD

But an informative website would attract their attention better,

"I would be encouraged to actually come to the DAFNE course if there's, like, a site that explains what it does, specifically." ND PWD

with testimonials from a range of people

"I'd want to see people that are like-minded… the same sort of lifestyles…a good range of people… so people can see the different results, it would be good." D PWD

or even allowing people to attend part of the course

"I don't know…almost do a taster day…" HCP

but that professional input with getting the marketing right for individuals was required.

"…you have to do your marketing analysis…with those different groups. You need to identify what …make them come." HCPs

Other methods of recruiting people to DAFNE were based on marketing to particular populations using public places, workplace and pharmacists.

"…football…all the things that you think people actually congregate, to actually work through…Game of Thrones, well, why don't we get a diabetic on that? (Laughter)…it's thinking of what actually, that they're up to, that you can hook into…" HCP

"Go to the workplace." HCP

"…we could set up a DAFNE signposting course for our black African males at the Jobcentre." HCP

"…if the pharmacist is handing out medications, and would be an amazing source of education resource for a patient…everyone picks up their medication…" HCP

14.2.4 Supporting the individual

The power of peer support was recognised by many, with varying degrees of engagement with this.

"It's definitely shared learning… you definitely get an awful lot from people…round the table… that's really, really good." HCP

"…[Glu - a mobile telephone app], a community of people who are all able to see each other's readings… give a bit of support, 'Oh, look, you're, you're high today, don't worry about it, it will come down', that kind of thing…" ND PWD

Some felt peer experts should be used more for the delivery of education and or support.

"I think patient experts get overlooked a lot." ND PWD

Peer support could be offered to individuals at diagnosis in a structured manner.

"…like when somebody joins a new company they get a buddy. They're that person that they can ask the stupid questions to…it's a good idea. Something I would have used…" D PWD

Although some were concerned about safety issues around peer delivery.

"I'd like to help if I can, but…it's difficult to understand what other people are going through, and I'd be quite nervous… [about giving] …the wrong information" D PWD

It was felt that this may work with a set of standards in place.

"…there'd need to be some level of buddy training …to make it actually work, you would need it to be clear that they're not, you know, medical practitioners… there to just offer you advice based on their own experience." D PWD

"…if someone's new… they can't expect 24/7 just like that, because that's quite unrealistic…" D PWD

One participant suggested that people should be given partners or buddies for the DAFNE course, to encourage faster learners to help others

"…just say, 'Okay, look, we're going to work in pairs…going to put you guys together'…if you're lagging behind, and slow, at least you've got a partner there who can help you out, and explain to you better." ND PWD

whilst HCPs felt that the DAFNE group was good at supporting individuals.

"…if you've got a good mix of people, and they gel, the other people help them out so much." HCP

"I think it may almost be more of a health literacy issue… we've had people who aren't very numerate, and, and they're fine. They might not be doing all the things, but they're fine, because they've had that supportive week." HCP

One HCP reported using a buddy technique for younger patients.

"…the transition and young adult groups, and I've tried to, sort of, buddy people up in a way to do that…" HCP

Yet there was a general disconnect between the PWD perception of the need for this support and HCP.

"…there was just that acceptance… that everybody can do it, and there was no upfront coaching, or just some basics around how you should actually work it out…" D PWD

There were mixed feelings about assessing numeracy skills prior to the course in order to offer that support, also reflecting this opposing opinion of HCP and PWD.

"…if I understood why you were doing it [pre-assessment questionnaire]…what the benefits of me might be…if the ultimate aim is to put you in the right group…I don't necessarily see that…a barrier" D PWD

"…you don't want to be putting people off before they get there, do they?" HCP

Some HCPs talked about the different ways that they or others try to help those with low numeracy skills.

"…simple as possible…with carb-counting and ratios and everything, you can make it complicated…you can actually…make it lovely and simple... even if it's not as accurate as perhaps you want to, it's enough to get good results from, and I think it's the skill of the person delivering it to bring it down to a level that that person can actually learn." HCP

"…the Oz DAFNE group have done a lot on literacy and numeracy issues, so things like having a decimal point, so they've taken that all off so it's a whole number…" HCP

"I had lady in clinic, where actually we needed to… working it [carbohydrate counting] out in a pictorial way as well…" HCP

"…everyone's got a mobile phone calculator, teach them how simply to do it on a calculator…" HCP

Additional areas where support was required were recognised; particularly for those who have not accepted their diagnosis.

"…they actually do need to know they've got a long-term condition, so that's the first step in selling it." HCP

"we're trying to fix somebody that actually d-, is in denial, doesn't want it fixed…" HCP

HCPs felt a need for specific communication skills training to move their patients closer to attending DAFNE

"So it may be that you may have to do some motivational interviewing before, just to see if they're ready to attend or not." HCP

"…it's because the people are just not ready [for DAFNE], they don't want to, and there might not be anything you can do …they just choose not to." HCP

Some participants recognised the psychological burden of T1DM and lack of holistic care offered.

"…we don't think of ourselves as patients, we're, we're people…it's mostly psychological, isn't it, and emotional? And then, you know, you go to the doctor, and everything's, sort of, medical and written down…" ND PWD

"…so the social, the, the psychological, and I think that's really what's missing in diabetes. We're sort of trying to put things in place, but we haven't solved… the underlying problems." HCP

Some do consider social aspects preventing attendance at DAFNE, providing supportive letters to employers

"I put in the letter … this is an investment in you as an employee… but obviously, some are…self-employed, or on low income. Those are the people that I find hard…" HCP

or offering financial aid to attend.

"we've got a charitable fund, and we offered-, I've offered childcare… transport, and hotels, and stuff…" HCP

14.3 Key points & Discussion

Five focus groups, using a mixture of stakeholders, identified four key themes to improve attendance at SE. The focus groups included people with T1DM who had completed DAFNE, as well as other forms of SE, and those that had never attended. This combination enabled PWD to question others reasons for self-management choices made, adding to the richness of the data. The HCPs invited to the focus groups included boroughs surrounding Southwark and Lambeth, providing a more generalisable opinion regards SE and raising issues such as availability and capacity that were unlikely to be identified without them. Involving all stakeholders from commissioner to patient allowed collection of broad opinions, allowing greater understanding of perceptions across the SE pathway and identifying disparities. For me, this process highlighted the importance of patient involvement in service delivery and redesign from the outset.

Four key themes were identified:

Organisation/Logistics:

- Centralised booking to increase capacity by sharing resources, but with ability to self-refer and book
- Provision for family and partner education, with recognition of the role they play in living with someone with T1DM
- Better data systems and connection of patient records between care providers

Alternatives:

- Modular approach with core modules.
- Blended learning, using digital approaches to reduce the burden on people to come to the hospital but maintaining elements of the peer support so appreciated by DAFNE attenders.
- Ease of access to additional quality online resources, to be accessed at own convenience
- Recognition of the role of peer support, and a potential role for peer experts
- Integration of education into clinical care, with a clear pathway and delivery of content at a point that suits the needs of the individual.

Marketing:

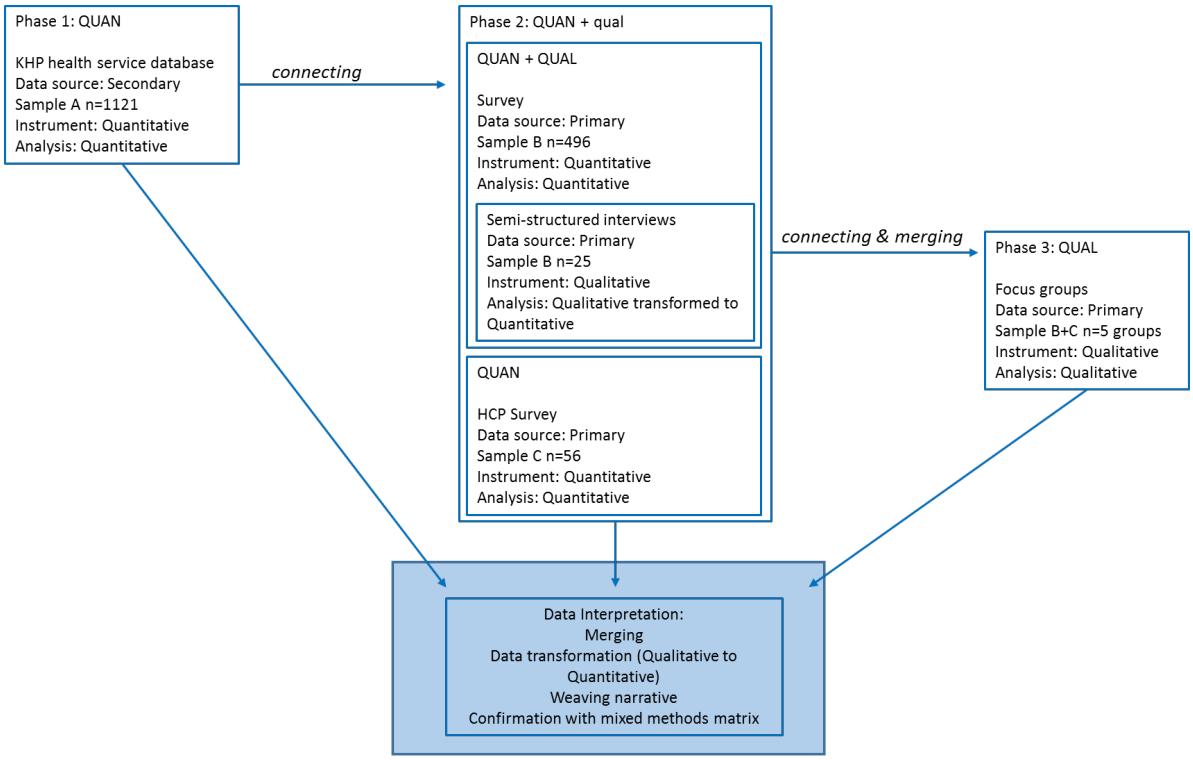
- Current marketing of DAFNE is poor

- HCPs influence uptake, but need to be trained or observe DAFNE to give consistent messages.
- DAFNE attenders would be well positioned to market to peers; suggested models included recruitment evenings, online or via clinic.

Supporting Individuals:

- Ability to complete the course at a pace suited to the individual
- Additional support for those with lower educational attainment, either with buddying or using technology
- Psychological support for those needing it and the use of motivational interviewing to help prioritisation of self-care and SE
- Financial support to attend either with funds or employers letter

15 Integration of results - Barriers



15.1 Methods

Integration of results has occurred throughout the project, with early results from each phase feeding into the design and integration of subsequent phases. However, as described in 7.2.3, integration has occurred at the end of the project, to bring together the findings from all three phases. This chapter examines barriers to attendance, using P1 and P2 data. The subsequent integration chapter examines potential recommendations for change, taken from P2 and P3 data.

Data have been merged using mixed methods matrices and weaving narrative to look for confirmation, expansion or discordance of results. Discordance prompted me to return to the original data to examine the phenomenon further and seek explanation. Mixed methods matrices involved comparing quanitisised data from interview transcripts to the validated scores given by participants who were both interviewed and completed a survey. These quantisised data were scored 1 to 3 and colour-coded red, amber and green to allow visual interpretation. I was primarily responsible for the scores given to interview data, but 20% of the transcripts were also read and scored by a service user to check interpretation of themes and validity of the scoring system. Scores were compared; disagreements discussed and moderated by third party where necessary. I used

narrative to follow a thread (specific topic) through the results, to reach a deeper understanding of complex issues (O'Cathain et al., 2008b).

15.2 Merging of results

Key findings from each phase have been used in the interpretation phase, to create principal themes upon which to base the merging of data and examine the consequences of using a mixed methods research approach. Three overarching themes, socio-economic, psychological and healthcare, were identified as influencing attendance at SE in south London. These themes have been used to illustrate my findings (Table 15-1) and form the basis for the structure of the discussion.

Themes		Phase 1 (quantitative)	Phase 2 quantitative	Phase 2 qualitative	Consequence of MMR
Socio-economic	Social	**Male** **Older age** BME	**Male** Age no different Born outside UK BME		Confirm: Male Confirm: BME Discordant: Age
	Economic	**Higher deprivation**	**Educational attainment** Numeracy Lower employment rates	Other time commitments as biggest barrier	Expand: Socio-economic determinants of health • Geographical deprivation • Education • Employment
Psychological	Depression		No difference in PHQ2 scores	3% recognised psychological (& 4% uninterested) barriers (low recognition)	Expand: Underlying psychological constructs producing typologies that were not apparent fron quantitative survey. • Acceptance/avoidance • Self-efficacy/experimentation • Self-worth
	Acceptance		PAID no different	Acceptance of diabetes required to enable self-care	
	Self-efficacy		CIDS no different Fewer sources of advice	Confidence in self allows experimentation 12% perceived low benefit as barrier Self-education	

Healthcare	Diabetes care	**Higher HbA1c (adjusted model >9%)**	**Higher HbA1c (adjusted model 7.5-9% & >9%)** 38% unaware of HbA1c result 20% in primary care only 26% HbA1c<7.5% and low hypo risk Lower use of complex regimen	Different barriers to attend by typology based on calculated risk (long/short-term complication avoidance)	Confirm: glycaemic control Expand: understanding of diabetes service provision and access. Expand: drivers/decisions for health
	Unscheduled care	Fewer admissions	More admissions (sick days same)		Confirm: influence (but discordance in relationsh of diabetes related admissions)
	HCP		**Positive HCP message** 1/3 not heard of DAFNE <4% referred did not attend DAFNE Ability to recognise low health literacy Misperception of attendance rate	Judgemental relationships & lack of continuity Different perception to barriers by care setting	Expand: Role of HCP

Table 15-1: Tabulation of key findings from Phase 1 and 2.
Three overarching themes were identified as influencing attendance; socioeconomic, psychological and healthcare. The key findings from each phase are illustrated within the context of these themes. Non-attender characteristics shown. ***Bold*** *signify variables found to be associated with attendance after adjustment in multivariate modelling. Consequence of MMR use is shown to check data confirmation, expansion or discordance between phases and maximal utilisation of MMR design.*

Where I found confirmation of results between the different phases, I have made no further exploration. However, where expansion or discordance has occurred and I have been able, I returned to the data to seek explanation (Fetters et al., 2013). This additional analysis is presented below. Where I was unable to return to the data, I have discussed the weight of findings and alignment with other studies.

There was discordance in recognition of psychological state influencing attendance at SE between the quantitative and qualitative data. The qualitative work identified a typology characterised by psychological issues; 'diabetes downers'. 20% of interview participants were 'diabetes downers' while only 3% of survey respondents recognised psychological barriers to attending DAFNE. This discordance prompted a return to the primary data for further investigation.

I analysed the P2 survey non-attender group according to likelihood of having depression or underlying psychological disorder, based on positive PHQ2 screening result or currently receiving relevant therapy (Table 15-2). There was no difference in demographics between those with and without high likelihood of depression but there were statistically significant differences in numeracy and health literacy scores. Those with higher likelihood of depression reported higher diabetes distress, lower confidence in self-care and lower quality of life. They had a greater use of NHS services, and greater likelihood of not attending appointments (DNA).

Table 15-2: Table of P2 non-attenders socioeconomic, psychological and service use variables per risk of depression. Categorical data shown as count and percentage (%). Continuous variables shown as median and inter-quartile range (IQR). Mean shown only for illustrative purposes where indicated. Statistical significance taken as p <0.05.

Variable	Likely depressed (91 (42%))	Unlikely depressed (126)	p value
Age (years)	35 (27-50)	36.5 (30-53)	0.244
Gender (male)	60 (67%)	81 (65%)	0.75
Ethnicity (white)	66 (73%)	100 (79%)	0.286
Numeracy (SNS)	4.5 (3.63-5.13)	4.88 (4.25-5.38)	0.002
Health literacy	4.5 (4-5)	5.0 (4.75-5)	<0.001
CIDS	61 (52-69)	71 (59-76)	<0.001
PAID	8.75 (4.4-13.8)	2.5 (1.3-6.3)	<0.001
QOL	7 (5.5-8)	8 (7-9)	0.007
Total service use	9 (5-18)	6 (4-11)	0.004
Total DNAs in 12 months	0 (0-1)	0 (0)	0.007

15.2.1.1 Weaving narrative of the effect of numeracy and health literacy.

The effect of low health literacy and numeracy on diabetes self-care has dominated my PhD. I followed this thread and used narrative to describe the findings from literature review through to final analysis of results. To maximise MMR design, emerging theories were investigated using quantisised data to confirm/contest findings across the study, as outlined in methods chapter 7.2.3.3). Two quantisised variables were used; numeracy and thirst for knowledge. The scoring of these has been described elsewhere (12.1). Some interview participants opted out of the survey or completed the survey anonymously, creating missing data. As more than a year had elapsed between conducting the interviews and this analysis, participants were not contacted to complete another survey, as their scores were likely to have changed with time.

A lack of gold standard measurement for health literacy and numeracy has been identified and the utility of educational attainment as a surrogate marker questioned. My literature review identified only three articles, confirming the insufficient interest from the academic and clinical world into the role of health literacy and numeracy on T1DM (8.4).

The P2 survey measured health literacy, numeracy and educational attainment. All were found to be significantly different between attender and non-attender groups. There was significant correlation between numeracy and educational attainment. Health literacy was not correlated, but was found to not influence self-care in the literature review. Therefore, numeracy and educational attainment were used interchangeably in this analysis and discussion.

Quantisised numeracy scores were compared to the validated SNS results for each interviewee (Table 15-3), suggesting inter-measure reliability. These scores were taken from one-hour interview data, where specific emphasis was placed on asking questions about numerical skills.

Table 15-3: Tabulation of the quantisised interview data according to my perception of each individual's numeracy skills in managing their diabetes, compared to the SNS score received in the survey (P2).
Numeracy score coloured from green through to red (higher to lower ability and SNS score similarly coloured green to red (high to low ability)

Study ID	2019	1236	2134	2358	1240	1120	1505	2359	4031	1769	1796	1105	1085	1374	1798	2634	1732	1134	2504
numeracy	1	1	1	1	1	2	2	2	2	2	2	2	2	2	2	3	3	3	3
SNS	6	5.875	5.75	5.625	4.625	5.625	5.375	5.125	4.875	4.75	4.625	4.375	4	4	2.875	4.75	4	1.375	1.25

The quantisised numeracy scores described above were compared to self-reported HbA1c for each interview participant. The results corroborate the relationship between numeracy and glycaemic control identified in the literature review (Table 15-4); individuals with low numeracy were unable to achieve an HbA1c below 8%.

Table 15-4: Tabulation of the quantisised interview data for an individual's numeracy score compared to glycaemic control, using self-reported HbA1c result (in DCCT%).
Numeracy score coloured from green through to red (higher to lower ability) with HbA1c coloured from light to dark brown (lower to higher HbA1c result).

Study ID	6001	2134	2358	1236	1240	2019	1105	2359	1769	1120	4031	1085	1505	1796	1798	6003	1374	1527	2634	6002	2504	1114	1134
HbA1c	<6	6to7	6to7	7to8	8to9	>10	<6	6to7	6to7	7to8	7to8	7to8	8to9	8to9	8to9	9to10	9to10	8to9	8to9	8to9	8to9	9 to 10	>10
numeracy - unable to re	1	1	1	1	1	1	2	2	2	2	2	2	2	2	2	2	2	3	3	3	3	3	3

Table 15-4 also illustrates that numeracy is not wholly responsible for glycaemic control and self-care, as some individuals with high numeracy were also unable to achieve a lower HbA1c (e.g. 2019). Other factors play a role, particularly psychological factors such as denial, that were identified via the semi-structured interviews. Additionally, two interviewees, in their honeymoon period, achieved a lower HbA1c despite a worse numeracy score than others (e.g. 1105).

The ability of one participant (in the honeymoon period) to achieve HbA1c <6% despite a mid range numeracy score is compatible with my theory that numeracy has a significant influence on glycaemic control in those with T1DM, due to the degree of numerical precision required for dose adjustment in the face of complete insulin deficiency. This is further supported by the level of control targeted by different typologies; 'Go getters', all of whom had high educational attainment and numeracy, targeted as-close-to-normal HbA1c as possible, preferring hypoglycaemia to hyperglycaemia whilst, those with low educational attainment 'trodden downers' aimed for higher HbA1c, preferring hyperglycaemia.

Lower educational attainment was associated with greater use of both unscheduled and scheduled diabetes services (in P2), suggesting lesser ability to self-care. Additionally, attendance at SE, which could be considered a marker of self-care, as it suggests proactive decision making, like receiving vaccinations or attending retinal eye screening, was influenced by educational attainment after adjustment for other factors in multivariate modelling.

The interview data suggested a complex relationship between numerical ability, confidence with experimentation and thirst for knowledge. I compared quantisised numeracy score to CIDS and the quantisised score for thirst for knowledge (

Table 15-5). Lower CIDS scores were found in those with lower numeracy. However, the two are not completely allied, suggesting other influencing factors.

Table 15-5: Tabulation of the quantisised interview data for an individual's numeracy score compared to validated confidence in diabetes self-care score (CIDS).
Scores coloured from green through to red (higher to lower ability).

Study ID	2358	1240	1236	2134	2019	1105	1374	1796	1120	1769	1798	2359	4031	1085	2634	2504	1732	1134	1527
numeracy	1	1	1	1	1	2	2	2	2	2	2	2	2	2	3	3	3	3	3
CIDS	79	76	69	68	56	73	73	72	71	71	68	61	57	53	62.68	59	58.68	56	32.68

The relationship between numeracy and thirst for knowledge appeared linear (They often did not know their HbA1c and reported lower complications, which may suggest a lack of knowledge rather than truly fewer complications.

Table 15-6); those with greater numeracy skills were actively finding information, whilst those with lower numeracy skills had less interest in finding information, or relied more on HCP interaction to receive diabetes related information. They often did not know their HbA1c and reported lower complications, which may suggest a lack of knowledge rather than truly fewer complications.

Table 15-6: Tabulation of the quantisised interview data for an individual's numeracy score compared to their thirst for knowledge.
Scores coloured from green through to red (higher to lower ability).

Study ID	1236	1240	2019	2134	2358	6001	1105	1120	1374	1505	1798	2359	4031	1085	1769	1796	6003	2504	6002	1114	1134	1527	1732	2634
numeracy	1	1	1	1	1	1	2	2	2	2	2	2	2	2	2	2	2	3	3	3	3	3	3	3
thrist for knowledge	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	2	2	2	3	3	3	3	3

Qualitative data suggest that thirst for knowledge was associated with locus of control and personal responsibility for health. Those who felt unable to control their diabetes themselves, or felt that it was someone else's responsibility, were less inclined to find information for themselves. This was related to self-worth; affected by previous judgemental relationships regarding their diabetes self-care ability (from parents or HCPs) or past educational experiences.

Most HCPs felt able to recognise low health literacy and adjust their diabetes treatment recommendation accordingly. This was confirmed in P2, where individuals with lower health literacy and numeracy were more likely to receive a less than positive message about DAFNE. This appeared independent of other demographic factors such as ethnicity. Additionally, there was a lower use of more complex (CSII and BD MDI) regimens in those with low educational attainment. The apprehension of trial and error, required to manage a basal bolus regimen (either by injection or infusion), is bypassed by using fixed dosing as illustrated in a selection of the 'trodden downer' transcripts. The 'trodden downers' described a preference for fixed dose regimens, by-passing the need for experimentation and reflection associated with basal-bolus regimen (12.3.3).

Low literacy or numeracy also affected attendance for the 'diabetes downers'. They described problems accepting their diagnosis and exhibited psychological distress. There was a higher rate of depression seen in those with lower educational attainment.

15.3 Discussion of Results

15.3.1 Socio-economic factors

Social determinants of health include many socioeconomic variables such as educational attainment, employment status, ethnicity and civil status (Marmot, 2010). Identifying the most influential of these intertwined variables is difficult but adjusting for variables in multivariate modelling allows some refinement of the understanding of most relevant variables.

Both P1 and P2 identified male gender as an independent barrier to attendance at SE, suggesting that it plays a hugely influential role. Male gender is recognised as a barrier to attendance in many other long-term conditions (LTCs), including T2DM (Coyle et al., 2013, Graziani et al., 1999). Gender differences cannot be fully explained by socio-economic status. T1DM affects a younger population than many other LTCs, and it has been hypothesised that employment is an explanatory factor in the lower rate of male attendance for T1DM (Wenzel, 2016, Pender, 2016). However, this study found male gender to be independently associated with non-attendance after adjusting for employment status. This indicates that other factors are influencing health seeking decision making amongst men. Attendance at SE may be considered a preventative or proactive intervention. Men are typically worse at accessing preventative medicine, which may be due to different access routes between men and women. Due to the need to attend family planning clinics young healthy women are twice as likely to consult a HCP (Office of Population Censuses and Surveys, 1991). This is thought to provide an initial contact and therefore route for onward referral to other services. Additionally, men appear to respond differently to symptoms of ill health, predominantly consulting HCPs for physical symptoms, rather than psychological (Moller-Leimkuhler, 2002). These findings have led researchers to theorise that differences in health seeking behaviour may be due to the concepts of 'masculinity' and the perceived weakness of seeking help (Galdas et al., 2005). This and other theories are yet to be proven.

Just as health seeking behaviours are influenced by gender, traditionally men are less likely to be involved in health research (Sheldon et al., 2007a). It is therefore interesting that my study managed to recruit sufficient quantities of men. I wonder about the role of selection bias, as those identified as 'go-getters' in the qualitative research were only male. I would anticipate this group of highly engaged individuals to be more likely to participate in research, and may therefore have self-selected and skewed the sample. However, review of those achieving HbA1c <7.5% in the survey responses indicates an equal gender split, making this theory less likely.

There was discordance between P1 and P2 regarding the effect of age on attendance. P1 found a significant difference in age between attenders and non-attenders (35 vs 39 years old), whilst P2 found no difference (38 vs 36 years old). The larger sample size of P1 makes this data more credible however the design creates some skew as DAFNE graduates prior to 2006 were included in analysis but had no controls. There was no difference in age between responders and non-responders in the P2 survey, suggesting that selection bias was not accountable. Previous research in LTCs has found age influences self-care behaviours but variably; cardiac rehabilitation studies identified older age as a barrier whilst pulmonary rehabilitation for asthma found younger age the barrier (Dunlay et al., 2009, Muntner et al., 2001, Suaya et al., 2007).

People from BME groups were less likely to have attended DAFNE in both P1 and P2 analysis. The significance of ethnicity disappeared on adjusting for other variables such as educational attainment and deprivation, suggesting that ethnicity was a confounder and not itself responsible for non-attendance at DAFNE. Qualitative data corroborate this with no evidence for barriers to attendance related to cultural beliefs or ethnicity. Other studies have similarly found other socioeconomic factors explain inter-ethnic variations (Powell et al., 2013, Osborn et al., 2011). This is corroborated via P1 subset analysis by ethnicity which found deprivation only remained statistically significant in the white group. Ethnicity and social deprivation have a complicated relationship, confounded by ethnic minority status and language barriers. This is corroborated by my finding lower attendance rates in non-British nationals. Although language barriers could be contributing, I consider this unlikely as my ethnically diverse population predominantly (80%) speak English, reflected in 87% of survey respondents reporting English as their first language (Table 11-1 (Census, 2011).

P1 identified over-representation of people from areas of high deprivation (measured by IMD) in the non-attender group. However direct comparison between P1 and P2 for markers of social deprivation was not possible as P2 did not measure IMD scores. P2 used other markers, such as employment status and educational status, to corroborate the effect of socio-economic factors on attendance.

Importantly, educational attainment continued to be an influential variable after adjusting for other socio-economic factors. The interplay of socioeconomic factors is complex and these studies were not designed to look for causality. However, what I have found is the significant role played by deprivation and ethnicity, but that above all educational attainment remains significantly associated with attendance after adjusting for these other factors. This suggests that educational attainment is key. This may be due to the inability to rationalise or compute benefit from structured education in

5041 those with low health literacy and numeracy. Educational attainment maybe a marker for other
5042 factors not explicitly measured in this study for example economic pressures making it difficult for
5043 individuals to take five days off work and perceived job security, or low self-efficacy leading to
5044 unwillingness or reticence of the level of responsibility required for insulin dose adjustment. These
5045 characteristics of low self-worth, external locus of control and low self-efficacy marked out the
5046 'trodden downers' from other typologies. Low self-efficacy has already been linked to health
5047 literacy, supporting this theory (Bohanny et al., 2013). The relationship between psychological
5048 constructs such as resilience, self-worth and confidence are emerging. However, social determinants
5049 of health are related to the ability to control one's own situation, leading to feelings of helplessness
5050 and hopelessness, culminating in external locus of control or fatalistic beliefs (Marmot, 2010).

5051 I did not find any cultural differences in health beliefs in interviewed non-attenders, but they may
5052 explain differences in measures of deprivation. Single or crude indicators of socioeconomic status
5053 such as IMD, which are based on geographical location alone, are less defining in ethnic minority
5054 groups in which greater social immobility may be a confounding factor (Karlsen and Nazroo, 2009,
5055 Graham, 2009). The Fourth National Survey of Ethnic Minorities in the UK found that within class
5056 groups, people of BME backgrounds have a lower income, are less likely to be home owners and less
5057 likely to increase their earnings (Karlsen and Nazroo, 2009, Oliver and Shapiro, 1997). A degree of
5058 chosen immobility may also exist as ethnicity provides social identity and marks a boundary between
5059 groups (Karlsen and Nazroo, 2009). Ethnic segregation is common in BME groups, with sense of unity
5060 and psychosocial benefit derived from local community, meaning some may choose to remain
5061 despite potentially being able to move into an area of increased which may explain the lack of
5062 relationship between IMD and attendance in BME groups wealth (Graham, 2009, Wilkinson and
5063 Pickett, 2007).

5064 Over the past 20 years, educational attainment within BME groups has improved (26% degree level
5065 qualification amongst black African 1991 to 40% in 2011) but employment rates remain static (full-
5066 time employment in black African 57% 1991 & 2011) (Sedghi, 2014). Men from BME groups are
5067 more likely to be in casual employment (Simpson et al., 2014). Racial discrimination and a
5068 perception of victimisation in the workplace are reported highly within BME groups and it is possible
5069 that they feel unable to reveal their diagnosis to their employer, and therefore do not feel supported
5070 to attend DAFNE (Karlsen and Nazroo, 2009, Karlsen and Nazroo, 2004). This high level of
5071 unemployment and casual work in people from BME groups suggests the need to prioritise job
5072 seeking over attendance at structured education

My literature review found numeracy to influence glycaemic control, but no influence of health literacy. My P2 survey found significant correlation between educational attainment and numeracy suggesting educational attainment could be sufficient marker of numeracy. This adds to current debate about how best to assess health literacy and numeracy, in the absence of a gold standard measure (Baker et al., 1998, Al Sayah et al., 2013). Educational attainment is likely to be better received by patients, less stigmatising and a less resource intensive measure compared to measures such as diabetes numeracy test (Huizinga et al., 2008).

15.3.2 Psychological factors

The role that mental health, particularly depression, played in enabling individuals to attend SE was not immediately apparent from the quantitative data. It only became apparent in the qualitative data; where one type was defined completely by psychological state ('diabetes downers'), and psychology played a role in two other types ('trodden downers' and 'not yetters'). This discordance may be because the proportion of people either receiving therapy or with a high risk of requiring therapy (PHQ2 score ≥2) (Table 11-3) was higher than expected (37% vs 10%) (Trief et al., 2014) . This is likely due to multiple reasons; first using the PHQ2 as a marker for depression, rather than the longer and more specific PHQ-9 , second the low sensitivity of the PHQ score for depression in diabetes (with 71% of participants in one study being identified via PHQ-9 as depressed (score ≥10) but not reaching clinical criteria) and third the inclusion of those receiving therapy without consideration of context (given that psychological therapies are used not only for depression but for diabetes distress and other psychological diagnoses) (Fisher et al., 2016, Li et al., 2007). Essentially, what was categorised as depression is likely to be a mixture of depression and distress, leading to over-diagnosis.

The past decade has seen an increased understanding of the differences between major depressive disorder, depressive symptoms and diabetes distress (Fisher et al., 2014). Experts have defined differences between these phenomena emerging from different theoretical backgrounds and requiring different interventions (Fisher et al., 2014, Fisher et al., 2016). Depression is a clinical diagnosis, with nine well-defined diverse symptoms and a defined duration (>two weeks). It is not disease specific and fails to distinguish between expected reaction and pathological response. Distress is more broadly defined; reflecting an emotional response (worry, concern and stress) associated with living with a demanding long-term condition (Fisher et al., 2010). Diabetes distress is not considered psychopathological, but 'part of the spectrum of diabetes' (Fisher et al., 2014, Gonzalez et al., 2011). These distinct emotional states have different effects on diabetes self-care outcomes; higher HbA1c is associated with diabetes distress whilst the relationship with depression

is still indeterminate, despite its negative impact on self-care processes, particularly concordance with treatment (Fisher et al., 2016, Fisher et al., 2010, Gonzalez et al., 2011, Polonsky et al., 2005).

To offer the correct intervention, recognition, differentiation and surveillance of these emotional states is necessary, and validated measures aid this (Fisher et al., 2014, Fisher et al., 2016). Different measures currently exist, including PHQ for depression and PAID or DDS for distress (Polonsky et al., 2005, Kroenke et al., 2001, McGuire et al., 2010). Recent work has assessed the utility of these scores. Considerable overlap was found with 95% of people with high diabetes distress scoring ≥ 10 on PHQ-9, suggesting the PHQ-9 is unable to differentiate the two different psychological states (Fisher et al., 2016). Additionally, distress cannot be measured in individuals with psychopathology preventing them from accepting their diagnosis. Individuals in denial often have low PAID scores, and it needs consideration in the context of other measures such as HbA1c (Polonsky et al., 1995).

Avoidance and denial are two coping behaviours associated with grief. The former is the effort to avoid dealing with or confronting a stressor and the latter is ignoring the presence of the stressor(Weisman, 1972). Denial has been described as having three levels, from denial of facts through to implications (Weisman, 1972). Oscillation between psychological states occurs and five stages of grief are recognised before reaching acceptance; shock, denial, anger, bargaining , and depression (Nash, 2013, Kubler-Ross, 1969). Movement between stages occurs but can become maladaptive or pathological if an individual is unable to progress to acceptance. Although based on palliative care research, these stages have been recognised in people with diabetes (Nash, 2013). My qualitative analysis recognised different psychological states, identifying a spectrum; from complete rejection, hatred, bare minimal management, accepting diabetes' presence but not making allowances, recognising that it needs to impact on life, to completely embracing it and changing life habits to integrate it into daily life (12.2.1.2). The first three states indicate maladaptive behaviours, and in accordance with the above theory these individuals have got stuck at one stage preventing them from moving towards acceptance, and therefore ability to self-manage. These individuals were categorised as 'diabetes downers'. People in the later stages had broadly accepted their diagnosis but experienced varying degrees of diabetes distress associated with the burden of their LTC.

Over 45% of people with T1DM are distressed by their diabetes but less than 10% have clinical depression (Fisher et al., 2016). Clinical depression in T1DM is associated with lower educational attainment and the number of additional life stressors .(Fisher et al., 2016) Resilience describes an individual's ability to deal adequately with stressors and achieve positive results despite them (Yi et al., 2008). The diabetes resilience model posits protective and risk factors associated with

behavioural and health resilience (Hilliard et al., 2012). They include individual, family, social and contextual risk factors. This builds on work showing that youths with self-care responsibilities beyond their cognitive capability have worse diabetes outcomes (Wysocki et al., 2013). My study confirms this, with depression being associated with lower educational attainment, higher unemployment and higher single civil status. For these individuals, the pressures of life are high. The addition of another stressor (diabetes) pushes them into a negative emotional state, not helped by their inability fully to conceptualise their diagnosis and low self-efficacy.

Self-efficacy is often included in composite measures of diabetes resilience (Yi et al., 2008). During thematic analysis, high self-efficacy defined another typology; 'go getters'. Again, the quantitative data did not identify these factors, with no difference in CIDS seen between attenders and non-attenders. However, the 'go-getter' group was defined by having high self-efficacy and internal locus of control. Twenty percent of interview participants fitted this typology, which was also defined by achievement of clinical targets (HbA1c). Twenty-eight percent of non-attenders in the P2 survey data had an HbA1c <7.5% and low risk of problematic hypoglycaemia. This P2 subset analysis (shown in (Table 11-13) corroborates the characteristics associated with 'go-getter'; university level education with associated high numeracy and more sources of information, with trend towards greater self-efficacy and lower diabetes distress. In contrast to the interview data, there was no gender split. One quarter of the likely low benefit group quoted low benefit as their main barrier to attending DAFNE.

Although this cross-sectional study cannot identify causality I hypothesise that these features, along with the capability afforded by university level education, drives these individuals to search out information, empowering them through knowledge, to experiment with their diabetes. The use of reflective learning increases their knowledge and confidence further, enabling them to achieve target glycaemic control with minimal risk of increased hypoglycaemia.

15.3.3 Health factors

Self-efficacy is included in the health belief model. The model uses perceived susceptibility, severity, barriers and benefits to predict engagement with health-related behaviours (Rosenstock et al., 1988). An individual's health literacy will affect perception of health and disease severity, explaining the effect asserted by health outcomes on attendance at DAFNE. Multivariate analysis in both P1 and P2 identified the role that HbA1c played influencing attendance. Both P1 and P2 found higher HbA1c influenced attendance; P1 found HbA1c >9% whilst P2 found HbA1c >7.5% was associated with attendance, but influence was greater for mid-range HbA1c (7-9%). This discrepancy is likely

due to timing of data collection. P1 used baseline (pre-attendance) data whilst P2 used current, self-reported data (from attenders and non-attenders). The baseline HbA1c of attenders in P1 was 8.4% (IQR 7.6 – 9.6%), hence a predicted improvement of 1% would move this range to 6.6 – 8.6% but the mean effect of DAFNE education diminishes over time and HbA1c is only 0.3% less than baseline within two years (Speight et al., 2010). There is anticipated overlap in the population sampled for P1 and P2, so although the results of P1 and P2 appear contradictory, they may well be supporting each other. An alternative explanation is the relative lack of HbA1c knowledge (38%) in the non-attender group skewing the data. Individuals unaware of their HbA1c result were compared to those with HbA1c <7.5% in P2 (Table 11-13). They had opposing characteristics to 'go getters'; particularly low numeracy and educational attainment. This is in keeping with research in T2DM showing lack of HbA1c knowledge is associated with lower educational attainment, as well as reduced self-care behaviours (Willaing et al., 2013). It further corroborates the interplay of numeracy and glycaemic control seen and discussed above and supports my qualitative data showing different types targeted different levels of control according to their capability. I speculate that the ability to minimise glucose variability and therefore safely target a lower HbA1c requires capacity to understand the interplay between ambient glucose readings, carbohydrate content, insulin on board, planned exercise and multiple other factors taken for granted by those with functioning endocrine systems. This is corroborated by greater rates of severe hypoglycaemia in those with lower health literacy with T2DM, explaining why my literature review found numeracy was more influential in T1DM than T2DM (8.4.4) (Berkowitz et al., 2014, Miller et al., 2010).

Unscheduled care was collected in both P1 and P2. P1 found previous hospitalisation influenced attendance and a non-significant trend (likely due to lack of power with insufficient admissions) towards greater admission rate in DAFNE attenders, whilst P2 found a significantly lower use of unscheduled and scheduled services in DAFNE attenders. Although these results appear opposing this is likely due to the data collection point and they are in fact confirmatory. Hospitalisation influences decision to attend DAFNE. Prior to DAFNE there is a greater hospitalisation rate in the attender group, which drops post-attendance. This finding is in line with DAFNE audit data showing 4.7% of people required admission for DKA prior to DAFNE training, reducing to 2.1% post-DAFNE. Our P1 data found similar admission rates prior to DAFNE (5.4% in the attender group vs 2.6% in the non-attender group) (Elliott et al., 2014). Length of hospitalisation is also reduced by DAFNE training (0.22 days vs 0.09 days) in keeping with national data (0.24 days admission for DKA prior to DAFNE training vs 0.08 days post-DAFNE) (Elliott et al., 2014).

The reason why more people attend DAFNE after diabetes-related admissions was not clear from my study, but I hypothesise that it is mediated by the individual's perception of severity in keeping with the health belief model (Rosenstock et al., 1988). Hospitalisation has far reaching personal impact and may offer a more tangible measure of severity than HbA1c. This may also be explained by political drive as the best practice tariff for DKA involves referral to structured education within three months of an episode. My qualitative data support this, with 3/4 typologies aiming for hospital/symptom avoidance rather than a targeted HbA1c. Additionally, hospital admission may prompt HCP referral to DAFNE or opportunistic communication of the benefits of DAFNE to a more receptive individual

The latter hypothesis of HCP influence is corroborated by results from P2 multivariate analysis that found receiving a positive message about DAFNE was associated with attendance. It is worth noting that this measure was entirely subjective and may reflect individual perception of message due to their psychological state, rather than a true difference in messaging. However, this finding was expanded further by subset analysis, HCP survey and qualitative data. This demonstrated that previous judgemental relationships with HCPs and lack of continuity were influencing non-attendance at DAFNE in the 'not yetter' group. It may be that those working within specialist care are best able to create these trusting relationships, as those with more experience of T1DM reported greater attendance rates within their clinics (13.2.3).

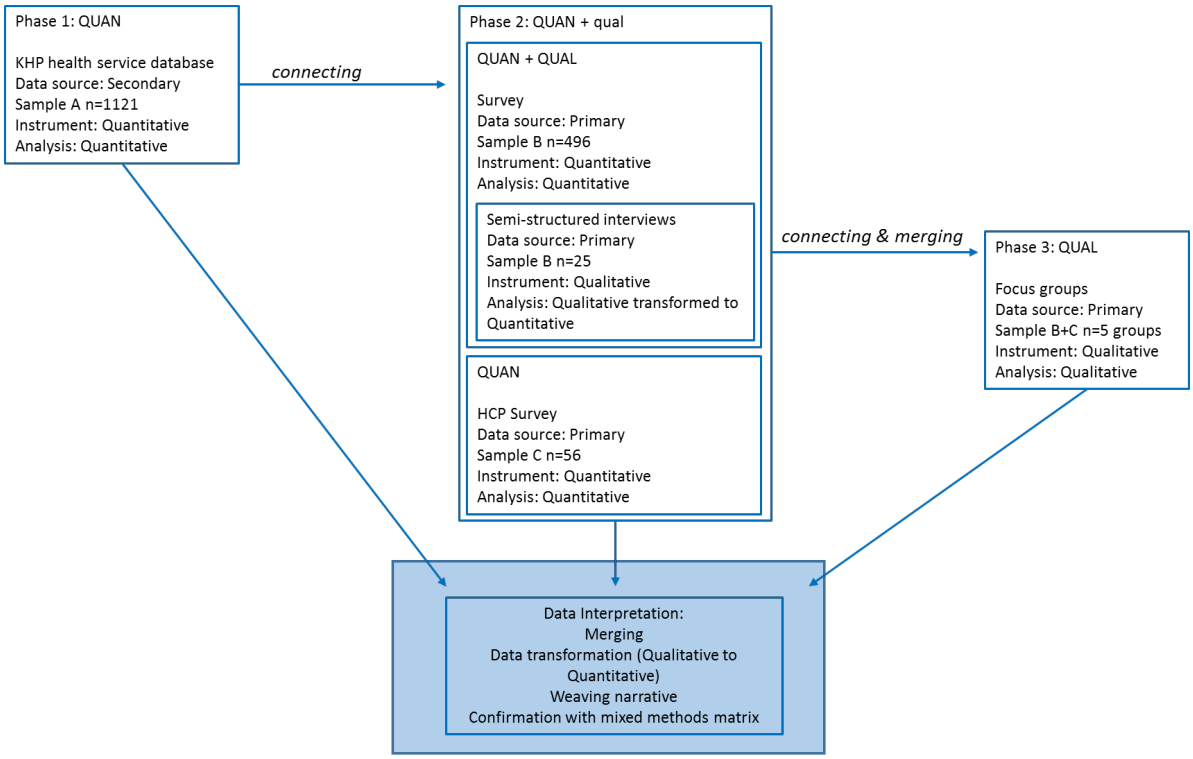
The low rate of referral but subsequent non-attendance at DAFNE (<4%) suggests screening of referral to individuals perceived as capable of completing the course. This is corroborated by P2, where 30% of non-attenders had not heard of the course and subset analysis found greater use of services was associated with more positive messaging about DAFNE. Although there was no difference in demographics between non-attenders receiving positive messages, their HCPs reported confidence in recognising low health literacy, and tailoring their consultation accordingly. Given the influential role of HCP messaging, it is worth noting the misperception of local attendance rate (50% vs 27%), and misalignment of perceived barriers between HCPs working in primary or specialist care.

The integration of results has broadened understanding. Some of the data expand previous knowledge, open the door to further question or theorise relationships. My studies were not designed to assess causality and any comments have been made as theories, with some evidence to support them where available. Particularly when discussing the interplay between socioeconomic factors, educational status and health outcomes or behaviours reverse causality must also be considered, for example the potential effect of hyperglycaemia on educational ability and hence

attainment with consequential effect on employment prospects and income. Further appropriately designed studies are required to examine these theories, particularly as much of the work has been done in T2DM, where long disease duration pre-diagnosis may make it particularly relevant.

Over 15% of respondents to the survey wer CSII users, while this may represent a response bias in favour of pump users, it may also be driven, at least in part, by local specialist services offering local as well as out-of-area patients pump therapy where indicated. Respondents also self-reported an average HbA1c 7.9%. This suggests a greater response rate from those more engaged with their care, as less than 30% of people with T1DM nationally achieve HbA1c <7.5% (Health and Social Care Information Centre, 2014). Mixing methods has allowed consideration of the degree of bias and therefore weight given to each phase during integration and analysis. Despite much effort to reach the traditionally harder to reach groups, BME groups remained slightly under-represented in the P2 survey. However, south London is unique in its diversity, making the results from this study more generalisable to other parts of the country and internationally. Plus, the effect of ethnicity appears to be a marker of socioeconomic deprivation, and not wholly related to BME status.

16 Integration of Results – Enablers, Motivators and possible Interventions



16.1 Methods

This chapter brings together the results from all phases using triangulation to consider enablers, motivators and possible interventions. The focus groups provided much of the data, integrated with results from the previous chapters (P1&2) allowing unified interpretation of all the data. The four themes to increase access to SE identified in P3, organisation or logistics, marketing, alternative education strategies and additional support, provided the backbone for integration. Evidence supporting and refuting these different approaches was then sought within the P1 and P2 data.

16.2 Results

Integrating and analysing all the study data (P1-3) showed evidence to support that the suggested strategies to enable attendance at SE would suit the need of most local PWD. However, no one strategy would single-handedly meet the entire population's requirements and elements would need to be developed sequentially to have maximal impact on increasing access. This is particularly relevant for those requiring psychological support or low numeracy, whose needs are not addressed

in the currently available course. Prior to improving system-wide logistics, marketing or organisation of a course or strategy to meet these specific needs requires development. The strategies and the supporting or refuting evidence is laid out in Table 16-1 and discussed further below. In the table, the first two columns summarise the findings from P3, and suggestions the participants in P3 made to address the barriers and support enablers for SE attendence by adults with diabetes, as they emerged from the analysis (14.2). The third column summarises findings from the integration of P1 and P2 data (Chapter 15) which support the value of the subtheme and the fourth column those data that argue against it.

Themes from P3	Sub-themes from P3	Advantages of this strategy from data	Disadvantages of this strategy from data
Organisation/ Logistics	Centralised booking Capacity Self-referral Flexibility	P1&2 Potential to reduce inequalities Reduce lag time from diagnosis to attendance P2 GG & NY likely to benefit Biggest enabler 'time logistics'	P2 Current courses not suitable for all Little evidence that culture plays a role Risk widening inequalities due to educational/digital capability and associated motivation. TD & DD lack self- confidence and reliant on HCPs
	Recognition of family and partner role	P1&2 Potential to reduce gender split P2 NY & TDs likely to benefit 17% attenders motivated by 'encouragement' to attend	P2 DDs unlikely to benefit, as alienate selves
	Better integration of health records/data	P1&2 Quantification & provision for harder to reach population. P2 Need for consistent message across 1° & 2° care Use of clinical changes to discuss perception of health	
	Integration of education into routine clinical care/pathways	P1&2 Remove barrier of male health-seeking behaviour Reduce lag time of diagnosis to attendance P2 GG, NY & TD likely to benefit 9% listed administration/marketing biggest barrier	P2 Current SE not suitable for certain groups
Marketing	Improved professional marketing	P2 30% not heard of DAFNE 9% listed administration or marketing biggest barrier HCP filtering referral Perception of benefit 20% solely in 1° care	P2 Current SE not suitable for certain groups

Themes from P3	Sub-themes from P3	Advantages of this strategy from data	Disadvantages of this strategy from data
	Skilled HCP marketing DAFNE	P2 Influence of HCP Perception of benefit HCPs with observation/more T1DM experience report greater attendance rates Likely to benefit NY & TDs most	P1&2 Socioeconomic/educational divide P2 HCP filtering NY historical judgemental relationships and wary of HCPs Differing perceptions across 1° & 2° care 29% of HCPs correctly recognised PWDs most quoted barrier to attendance.
	Peer marketing DAFNE	P1&2 Socioeconomic/educational divide P2 HCP filtering Perceived benefit Benefit NY (wary of HCPs & motivation) Majority attenders motivated by 'knowledge' acquisition	P2 Current SE not suitable for certain groups
Alternative education strategies	Modular approach with core modules.	P2 Time logistics and duration biggest enabler to attendance Perceived benefit Tailored course	P2 Unlikely to benefit DD
	Blended learning (digital and peer support elements)	P2 Time logistics and duration biggest enabler to attendance Uniformity of teaching style identified as barrier GG recognised value of peer & online support Likely to reduce gender split	P1&2 Risk of increasing educational/digital divide P2 DD, TD & NY may not use
	Access to quality information	P2 GG using online information NY & TD currently underutilising Likely to reduce gender split	P1&2 Risk of increasing educational/digital divide
	Use of peer support/educators	P2 Encourage NY to attend High psychological burden	

Themes from P3	Sub-themes from P3	Advantages of this strategy from data	Disadvantages of this strategy from data
	Tailored education to personal requirement	P1&2 Reduce socioeconomic, educational and gender divide P2 Perceived benefit Time logistics and duration	
Additional support	Tailored pace to personal capability	P1&2 support socioeconomic/educational divide Perceived benefit Individualised/tailored need Benefit GG, NY & TD	P2 May not benefit DD
	Support for low numeracy	P1&2 support socioeconomic/educational divide P2 impact on self-confidence Individualised/tailored education Benefit TD & DD	P2 No benefit GG & NY
	Psychological support	P2 High prevalence of depression/distress support DD & NY	
	Financial/employer support	P1&2 support socioeconomic/educational divide P2 Work and time commitment biggest barriers to attend Support NY & TD primarily	P2 No benefit DD

Table 16-1: Table illustrating the four themes identified in P3 (focus groups), with evidence supporting or refuting the utility of these strategies taken from P1 and P2 data. GG = Go-getters, NY = Not-Yetters, TD = Trodden Downers, DD = Diabetes Downers

16.3 Discussion

The emerging themes enabling increased attendance at SE from P3 are broadly supported by the data from P1 and P2, but it is clear from the table that no one strategy or intervention will immediately address all the current barriers identified, indicating that a tailored approach is necessary. In particular, different approaches are required to address the needs of the four different types identified in P2 to help them each attend SE, although some interventions would meet the needs of more than one type. To meet the key challenges of the Five Year Forward view, one could target the largest group, however improving the 'quality and care gap' requires attention to those most in clinical need, who may not be the most numerous (Stevens, 2014). Most interviewees were 'not yetters', however there was a higher than anticipated number of survey respondents with evidence of depression. A quarter of non-attenders achieved an HbA1c <7.5% with low risk of hypoglycaemia, suggesting that this population of 'go-getters' should be less of a priority in the currently austere healthcare climate. They should be identified and provided with tools to allow them to self-care. They would benefit from DAFNE at an early stage in their diagnosis, prior to self-educating to the extent of no longer perceiving benefit from the course. This would suit an integrated pathway, where transparency as to when the course was going to be offered, and/or the ability to self-refer and take control of scheduling the course. Identified later in their disease duration, this group may not need DAFNE; given that the evidence for efficacy is based upon an HbA1c >7.5% (without problematic hypoglycaemia), and, in the absence of data showing that further benefit can be obtained by attendance at SE, providing access to high quality, safe information in other ways may be a more cost-effective way to support their on-going to self-care. Access to quality assured online information may also improve engagement with self-care for many, particularly men, who are more likely to turn to the internet for health advice (Mens Health Forum).

The remainder of this discussion will concentrate on the other three groups; whose need is greater. The currently available SE was not suited to both the 'trodden downers' and the 'diabetes downers'. They require additional support to facilitate their diabetes education, and enable self-management. The 'diabetes downers' require psychological support to help them come to terms with their diagnosis, and move through the five steps of grief occasioned by the loss of their perceived health (Kubler-Ross, 1969). Provision of psychological support may be a wider need. One quarter of interviewees were categorised as 'diabetes downers' but almost half of survey respondents were identified as having high risk of depression. There were elements of psychological distress in both the 'not yetter' and 'trodden downer' groups, all suggesting a role for increasing psychological support throughout T1DM. However, the intervention required may differ for each group. In some

cases, attendance at DAFNE or peer support networks (either virtual or real) should be sufficient as there is evidence for psychological benefit from attending the course, with reduced rates of screening positive for anxiety and depression rates (DAFNE Study Group, 2002, Due-Christensen et al., 2016, Fisher et al., 2012). Others may need specific psychological therapy or medication for underlying psychopathology. Effective measures to define distress and depression are required to aid identification, make diagnoses and evaluate improvement of mood states (Polonsky et al., 2005).

Many of those in the 'diabetes downer' group also had low educational attainment, suggesting a role for educational support in this group as well as in the 'trodden downers'. This additional support should include re-design of the current course to be accessible to people with low literacy and numeracy. An alternative approach would be to provide training to improve literacy and/or numeracy, with potentially wide ranging benefits, prior to course attendence. Re-design could include the use of technology such as digitalised carbohydrate ready reckoners and bolus calculators shown to improve patient satisfaction and glycaemic control (Colin and Paris, 2013). This would need to be supported and underpinned by education. We know, for example, that people with low numeracy using CSII appear to use fewer of the technological features of this therapy (Patrakeeva et al., 2013, Schwartz and Guo, 2012). Alternatively, the curriculum could be modified, using educational philosophy, to suit the national average reading age (Williams et al., 2003). Involvement of an educational psychologist would provide elements to build self-worth and confidence in experimentation. Some generic programmes, such as 'Co-creating Health', are currently using this approach (Wallace, 2012). A similar approach has been used in the adolescent T1DM population with positive clinical outcomes reported (Eiser et al., 2013, Diabetes UK, 2015). However, disguising diabetes education in other activities such as go-karting may not be appropriate for the 'trodden downers', who appeared keen to participate.

Another strategy to support those with lower numeracy may be via delivery of a course at a slower pace. This would allow those that were struggling with certain concepts to spend time getting the basics right, before moving on to the next lesson. Additional training would be required for educators. Awareness of an individual's capability alone is insufficient to improve outcomes (Seligman et al., 2005). This strategy should reduce the socioeconomic divide secondary to educational attainment. It would also provide a more tailored course, with potential to move faster through course materials for those with higher educational attainment, or previous self-education, overcoming the issue of low perceived benefit to both the 'go getter' and 'not yetter' groups. The delivery of this strategy might require a pre-assessment of ability to stream similar capabilities. Although there is no current gold standard for identifying diabetes numeracy, educational

attainment appears to be a sufficient surrogate. An assessment could be done to identify those requiring specific support to improve numerical skills. This could be in partnership with existing government strategies to increase national numeracy and literacy by 2020, such as national numeracy challenge (National Numeracy Challenge, 2015, The Public Accounts Committee, 2009).

Assessment pre-attendance should be able to identify not only educational but also lifestyle-specific requirements, enabling a more tailored approach to both marketing and delivering the course. Identification of knowledge gaps could be used to help motivate attendance, particularly in the 'not yetter' group, as most DAFNE graduates accredited their attendance with knowledge acquisition with.

A 'pre-assessment and tailor-to-need' tactic would suit a modular learning approach. This could split the current five-day course into shorter duration, enabling attendance for the many that felt time and work commitments were their biggest barriers. Development of gender-specific modules, coupled with professional marketing strategies, may encourage greater attendance in males (Hjelm et al., 2005). Additionally, provision of modules of advanced level education, dealing with more complex concepts, may attract 'go getters' (and completers of SE courses) and enable them to achieve near normal glycaemic control.

NICE set out certain standards to define structured education with no minimum duration or a specific curriculum (although the need for a curriculum in the course is an essential feature of SE) (National Institute for Health and Care Excellence, 2015). The DAFNE course has proven clinical effectiveness, however there are many elements; the curriculum, the duration, peer support and the face-to-face delivery (DAFNE Study Group, 2002). It is hard to determine which of these elements, or combination thereof, are necessary to deliver the outcome. DAFNE centres are moving towards delivering the curriculum over five weeks, providing an element of modular teaching. This risks altering the fidelity and worsening outcomes, particularly as there is currently little evidence for efficacy of this delivery mode. This five-week model still requires commitment to all five days and is therefore likely to remain unattractive to many. A truly modular approach would provide small stand-alone courses, that would slowly build knowledge and offer education at specific time points to fit clinical need, for example pregnancy or complications. This would build on the key principles of adult education; goal setting, experiential, problem-based and immediately used (Knowles, 1984). However, it is essential to note that such a significant re-design of delivery mode would need to be tested, to ensure equivalent (or improved) outcomes to existing courses. It has to be acknowledged

that learning the necessary skills for life-long insulin self-management has to occupy some dedicated time.

Just as it is difficult to define the optimum duration of education courses to achieve outcomes and attract attendance, it is also hard to define whether the method of delivery plays a role. Teaching style and requirement to attend in a group posed a barrier to some, whilst DAFNE attenders were strong advocates for the peer support aspect of the course in retrospect. A blended learning approach was suggested, with elements of face-to-face alongside online. This may help the 'not yetters' overcome their fear of being judged for their diabetes management styles. A solely online offering may further overcome the nervousness of group education but may weaken the ability of the current SE to help PWD realise they are not alone, and the learning they take from each other (Snow et al., 2013).

An online or blended approach would also enable more people to overcome the barrier of work commitments, as part of this could be delivered out of normal working hours, or allow remote connection to online material. Digital approaches to diabetes education show benefit and provide flexibility and individualisation, which many asked for (Pereira et al., 2015). Additionally, male preference for seeking health information online means men may be encouraged to increased engagement with SE provided in this medium (Bogle, 2015). However, this risks potentiating inequalities: the 'go-getters' were the only group reporting actively seeking information or self-educating. This is supported by probing at interview revealing other underlying reasons, indicating that although time and work commitment barriers are initial responses (Joffe, 2011), further questioning uncovers more dominant unconscious reasons for non-attendance. Therefore, supporting attendance for example by letters to employers and financial support is unlikely to yield much benefit as there are deeper seated reasons for non-attendance. This is illustrated by the many 'not yetters' who had been given permission from work to attend but remained unwilling, largely because of concerns about stigma.

An approach based predominantly on digital provision risks increasing socio-economic divide as those without access to computers, or those with digital illiteracy, would be unable to attend the course. My population, particularly given the young age group affected by T1DM, have a low risk of digital exclusion due to access, although this statement does not consider digital literacy which is linked to educational attainment (Southwark Council, May 2014, Go On, 2015). Previous research in other LTCs has used digital approaches to deliver education, but although overall use was

satisfactory, there was marginalisation of those with low literacy (Sarkar et al., 2012, Sarkar et al., 2011).

Despite these concerns, a recent King's Fund review identified gaps in the diabetes education offering for T1DM, with few informal or flexible courses available (Wenzel, 2016). A modular, online or blended approach would provide a suite of different learning options to suit individuals and their different learning styles (Pereira et al., 2015). Inter-generational differences in how people wish to access their information may exist and this may be further influenced by level of educational attainment (Lai and Hong, 2015, Bennett et al., 2008, Sarkar et al., 2011). Those who achieved university level education will be used to problem-based learning and finding information for themselves, compared to those with only primary school education, who will be used to content-based learning and may not have developed an investigative learning style (Pashler et al., 2008).

Delivery of an effective modular approach would need sufficient support via integration of health records. This would allow PWD and/or their HCPs to see what modules have been completed, and build upon existing knowledge. HCPs would be able to use data, such as recent laboratory results or hospital attendances, from primary and specialist care to help conceptualise disease severity and hold meaningful conversations about benefit of attendance. This would build on the evidence for effect of HbA1c in both P1 and P2 data. Sharing health records would also allow a consistency of message across care settings about the importance of SE, and would benefit 'trodden downers' who had high reliance on all HCPs and rarely filtered messages (White et al., 2013). It would also improve continuity of care, essential for building trusting relationships and motivation to attend for the 'not yetter' group.

Integration of patient level data, as suggested in national government policy, would afford complete oversight of attender and non-attender groups, driving innovation of SE to meet the needs of the non-attender groups (HM Government and NHS England, 2014). Areas using integrated health records have seen improved clinical engagement outcomes, however biometric measures are yet to improve (Diabetes UK, 2015). The current annual National Diabetes Audit collects some of these data, but not real-time or with the granularity required to drive meaningful local improvement (Health and Social Care Information Centre et al., 2016). As well as driving innovation to improve attendance within certain socio-economic groups, integrated patient data systems would enable PWD to move care providers, whilst remaining on waiting lists for diabetes education courses (a problem predominantly for 'go getter' and 'not yetter' groups).

Waiting lists were rarely mentioned by PWDs, likely due to the regularity of provision of DAFNE in the two boroughs investigated. However, it was mentioned by HCPs and PWDs with experience outside Southwark and Lambeth. Waiting lists were predominantly due to insufficient capacity or irregularity of courses. Centralising the delivery or booking of DAFNE across south London would enable increased capacity via sharing of resource. This would reduce waiting lists. It would also offer flexibility of time, venue and type of course. This could reduce inequalities in attendance associated with geography and the lag time from diagnosis to attendance. It would also allow cost-efficient delivery of specific courses, for example in mother tongue, across a larger geography. However, there was little evidence that culture played a role in non-attendance, other than the confounder effects associated with educational attainment. Moreover, there is currently insufficient choice to cater for educational or linguistic needs.

An alternative to offering patient choice, including self-referral options, would be to remove choice. The former strategy risks alienating many groups; the 'not yetters' would continue to procrastinate, whilst the 'trodden downers' and 'diabetes downers' would put off attendance due to low self-confidence or denial. Integrating diabetes education into clinical pathways removes choice. It removes the need cognitively to prioritise, as it becomes the norm and expected. Non-attendance rates at a clinic appointment are 16-13%, and this may translate to SE if fully integrated into clinical care and given the same status. Integration into routine care would utilise popular government strategies, via social norming of attendance and removing logistical barriers to make it easier (Halpern, 2015). It would benefit most groups identified, bar 'diabetes downers' who have higher DNA rates (Table 15-2).

Without appropriate marketing, there are mixed messages about the importance of SE and what it involves. This was illustrated by 30% of the eligible population not having heard of DAFNE, and the 9% of non-attenders for whom 'administration or marketing' was the biggest barrier to attending. Interview data suggested it played a larger role, being linked to perception of benefit, as insufficient detail made it difficult for individuals to gauge benefit to self. Three different strands to improve marketing were recommended; HCP, peer and professional.

HCPs were seen to play an influential role in attendance; however, they also appeared to refer selectively, based on unsubstantiated criteria, such as educational achievement. HCPs are in a unique position; most PWDs need at least annual HCP review and insulin prescriptions. Every contact should count, providing an opportunity to improve patient outcomes by empowering self-care via SE (Public Health England et al., 2016). Improved marketing by HCPs would benefit both

'trodden downers', who are heavily reliant on HCPs advice, and 'not yetters' (White et al., 2013). This latter group would only benefit in the face of improved continuity in care, as they described previously judgemental HCPs and lack of nurturing professional-patient relationship. Only 29% of all HCPs correctly recognised the most often quoted patient barrier to attendance. Therefore, a cohesive approach is required to overcome this and the disconnect between perceived barriers from primary and specialist care. This approach may include motivational interview training to help to move the 'not yetter' group closer to activation, and readiness to attend (Channon et al., 2005, Bos-Touwen et al., 2015, Hibbard and Gilburt, 2014).

Those HCPs who had greater experience of caring for T1DM or had observed a DAFNE course reported greater attendance rates. This suggests observation of a DAFNE course would be a good strategy to improve HCP knowledge of the course and their marketing ability. Alternatively, T1DM should be cared for by specialists with sufficient experience, as suggested in local guidance (London Strategic Clinical Network, 2016). P2 data showed this was not the case, with 20% of non-attenders being cared for solely in primary care.

A second strategy, professional marketing of DAFNE, would over-ride the role of the HCP, overcoming the barriers they present, particularly filtering referrals and inadequate marketing. A professional marketing strategy would reach those in primary and specialist care, providing sufficient information to allow informed decision making and reduce perception of insufficient benefit. Tweaking the marketing message to pique interest of certain groups would help reduce inequalities.

Part of this marketing strategy may include the use of significant others which may be of particular value in reducing variation in male attendance. Male health-seeking behaviour may be overcome through involvement of female family or friends (Mens Health Forum). Not only could attendance be encouraged by messaging to loved ones, but also providing education for them. Most groups would benefit from this approach, apart from 'diabetes downers' who tended to alienate themselves. 17% of people reported 'encouragement' from others as their biggest motivation to attend DAFNE. The 'not yetter' group, who lack motivation, may be helped to prioritise attendance by supportive others. 'Trodden downers' who relied heavily on reassurance from those around them, may also benefit. The approach would help those with low self-confidence, nervous of group education, and has shown benefit in low socioeconomic groups with T2DM (Vissenberg et al., 2016). It would improve public knowledge of diabetes, as well as enable better management during diabetic emergencies if third party assistance was required.

A third marketing strategy is the use of peers. Messaging of the benefits from the course are likely to be very different from a PWD compared to HCP. This could alter perception of benefit and improve uptake. DAFNE advocates or champions could be found from all walks of life, helping to reduce health inequalities by creating conversations with 'someone like me' and social norming attendance. Less than 10% of survey respondents speak to someone else with T1DM about their diabetes, making it very difficult for them to find out information about SE and other advances in the diabetes world. For the 'not yetter' group this strategy would be particularly powerful, as many of them were weary of HCPs, lacked trusting relationships and were nervous about being judged by the group. These fears could be allayed by a peer.

Alongside marketing, peers could be used to deliver education, bridging the gap between clinician theoretical education and day to day experience (Wiley et al., 2014). This model has been used in other long-term conditions, with success (Murray et al., 2012, Deakin, 2005, Carey et al., 2014). It reduces delivery cost (as they replace a HCP), increases capacity, enables delivery of culturally sensitive SE and provides additional benefit from shared lived experience (Zeh et al., 2012). Patient experts are recognised for their ability to provide psychological support by understanding, first-hand, the experience of the group and may even improve health literacy (Piette et al., 2013). There is a need for greater psychological support within diabetes, and this may provide a strategy.

Overall, I have identified multiple potential interventions to enable increased uptake of SE. Some of these, risk further alienating certain groups and increasing health inequalities. To minimise this, there needs to be a considered application of these strategies. The order in which these are implemented is important and design of a SE course to meet the needs of those with low educational attainment should be a priority. Any redesign of SE will need to be robustly evaluated to ensure outcomes are equivalent to current gold standard, and that the course meets NICE quality standards. HCPs play an important role in promoting SE, but need to be cognisant of the fact that time and work commitment appear to conceal more fundamental barriers associated with prioritisation and fear of judgement. Providing motivational interviewing skills to HCPs involved in management of T1DM and other LTCs may reap multiple rewards, beyond attendance at SE.

17 Conclusion of presented work and future direction

My mixed methods study has taken a whole systems approach to investigate reasons for low attendance at SE by adults with T1DM living locally. I have involved commissioners, providers and people with T1DM, gaining a deep and broad understanding of the subject by using both qualitative and quantitative methods. Although my studies focused on SE in FIIT self-management for adults with T1DM, the lessons learnt have relevance to people living with other long-term conditions – I chose T1DM because of the complexity and relentless needs of managing insulin replacement in the situation of complete insulin deficiency.

The use of a large service-use database allowed me robustly to determine the number of local individuals that have attended DAFNE, the relevant local SE offering. This circumvented selection bias, and enabled me to identify barriers associated with gender, social deprivation and age. It also pointed towards the role HbA1c, the biochemical marker of the effectiveness of insulin therapy, plays in influencing attendance. The 27% of people attending DAFNE is far greater than the currently captured NDA data, and may be slightly greater given that the DAFNE database used was local, rather than the central database and there is a great resident turnover in our central London boroughs. Therefore some 'non-attenders' may have attended DAFNE in areas outside of Southwark and Lambeth or completed an alternative diabetes education course. The survey data added to the information from the database by confirming the role of social determinants of health, indicating that this was likely mediated by educational attainment. The correlation between numeracy and educational attainment made it difficult to identify the most influential of these. My literature review suggested that numeracy was more important than health literacy, although it should be noted that I excluded studies measuring educational attainment alone as at that stage the evidence suggested that it was an inadequate marker of numeracy and health literacy. This can now be re-visited, in view of my findings. My survey data has added to the field of health literacy, by showing a co-linearity between educational attainment and numeracy; suggesting that it can be used as a surrogate marker. Indeed, my data support the routine documentation of educational attainment as being of clinical value as a screening question in assessing the needs of people with LTCs, later corroborated with a validated and more sensitive score such as Newest Vital Sign (Khazaezadeh et al., 2012).

The database and survey of PWD suggested a role for perception of disease severity influencing attendance. This was reflected by the effect of HbA1c on attendance, and also evident in the role of HCP communication about SE on attendence. The HCP survey suggested a degree of HCP filtering

referral to SE according to their perception of their patient's ability. This was also apparent in the qualitative focus group work, but does require further investigation to confirm the hypothesis.

My study focused on recognising specific barriers to attendance in order to develop strategies to overcome these. The qualitative research identified four types of non-attenders, according to clear characteristics, and subsequently strategies suited to each. The T1DM population of Southwark and Lambeth needs now to be considered as whole to determine priority of interventions. Table 17-1 summarises my study findings. It shows that just over one quarter of eligible PWD have attended DAFNE. The remaining non-attender group is divided between the four types, with the 'not yetters' making up the majority (23%).

Table 17-1: Table outlining the different groups identified in the BUDiE study. The table shows the likely percentage of the total T1DM population fitting into each group, suitability for the currently available SE course, the main barrier to attendance at SE and the likely most beneficial intervention.

Type	DAFNE suitable	% of T1DM population	Main barrier	Main intervention
DAFNE graduates	Y	27	x	X
Go-getters	Y/N	15 - 20	Self-education	Information & support (HCP, peer, virtual)
Not-yetters	Y	20 - 30	Judgmental relationships	Integration Motivational interviewing Peers – social norming
Trodden-downers	N	15 - 20	Low numeracy	New courses to support numeracy
Diabetes-downers	N	15 - 20	Denial of diabetes	Psychological/Psychiatric treatment

The 'go-getter' group (15-20% of the total population) is suitable for DAFNE, and would benefit if provided at any early stage in their diagnosis, however may not require it now, as they already achieve HbA1c <7.5% without problematic hypoglycaemia. This group needs to be provided with access to information and support to self-manage, with minimal input from HCPs, which would free up NHS capacity to concentrate on the other three groups. This is something that I have started to implement through the creation of a website (www.t1resources.uk). I brought together a group of HCPs and people affected by T1DM (both patients and carers) to review currently available online resources. Each resource undergoes both peer and HCP review, to assure quality and safety, prior to being added to the site. The website brings over 350 quality assured and trustworthy resources into one easily accessible place. It launched in September, and has about 1,000 users per month. It has been supported by third sector as well as NHS organisations, with backing from Dr Partha Kar,

Associate National Clinical Director for Diabetes at NHS England. The website will be sustained in the long-term, beyond my PhD.

The 'not yetter' group (20-30%) have the capability to successfully manage FIIT. They would benefit from motivational interviewing, and the development of strong collaborative relationships with their HCPs to overcome feelings of stigma about their diabetes self-management, and activate them towards DAFNE attendance. Most of this group had been diagnosed as children and described judgemental HCP relationships, particularly common in teenage years (Snow and Fulop, 2012). This transition period is a fundamental period to support individual's independence in self-management. The service specifications for transition care do not specifically deal with SE (NHS England, 2016a). However, integration of SE into the clinical pathway, expectation of attendance within a few months of joining adult services, peer support with social norming and virtual clinics are all potential strategies to create better relationships and encourage attendance (Thynne et al., 2014).

Table 17-1 suggests a target of 50% attendance rate is possible from the above two types. However, 30-40% of the T1DM population are alienated by the current provision, as it does not suit their needs. There was a great deal of overlap between the 'trodden downers' and the 'diabetes downers' groups. All of the 'diabetes downers' had underlying communication difficulties, making it hard for them to conceptualise their diagnosis and come to terms with it. For most, this was due to low numeracy and health literacy. Therefore, about 30-40% of the total population need educational materials and support targeted closer to the national average ability, rather than the current level (The Public Accounts Committee, 2009, Kerr, 2010). This does not mean that the principles taught by the current DAFNE should not be made available to them, rather the same knowledge and skills need to be delivered using different media and systems, as further explored below. It is not surprising to find 30-40% of my sample to have low numeracy given that 75% of the UK working population have less than level 2 maths skills. What is astonishing is that I found such a large proportion of the population with an unmet need. There is a current lack of interest in this group, reflected by the limited number of articles on this topic identified for my literature review. Without adequate measurement of this problem, there will continue to be no impetus to make changes to accommodate the people with it. However, numeracy is not the only problem for these two groups. Half of the people in them, the 'diabetes downers' (20-15% of total), also require psychological and/or psychiatric support to help them move towards acceptance of their diagnosis (Kubler-Ross, 1969). A diagnosis of T1DM is a bereavement, as the person loses their concept of themselves as healthy and well, and as with bereavement, needs to come through a series of adjustments to

emerge with a mental ability to handle the loss. Until these individuals have accepted their diabetes they will not be willing to attend a SE course.

Chapter 16 describes multiple different strategies to improve attendance at SE but emphasises that the timing and sequence of implementation of each strategy must be considered. This is most important for the marketing and organisation/logistic strategies, which ideally need to be preceded by an approach to provide access to SE for those with low numeracy. As discussed, this could take on many guises; from use of technology, providing skills to improve global numeracy or designing a new SE course. The design of this intervention should use collaborative approaches; involving psychologists (both educational and behavioural), as well as PWD and their support networks. A new SE course will need to be robustly evaluated and meet the quality standards outlined by NICE (National Institute for Health and Care Excellence, 2003a, National Institute for Health and Care Excellence, 2015). In terms of evaluating this new intervention, consideration will need to be given to the baseline capability of the population and appropriate adjustment made to account for this, in place of direct comparison with the current gold standard SE (DAFNE). This course should not be a diluted version of DAFNE, as the people for whom it is intended should be supported to develop the same skills and achieve the same outcomes as are the aim of current DAFNE. This would be a large piece of work, and something that I am interested in developing as a post-doctoral fellow. My current research suggests this group of patients are most in need, with greater use of unplanned services, greater reliance on HCPs for advice and higher HbA1c. Their needs should therefore be prioritised, as the potential cost-saving made through improved self-efficacy within this group is great. A review of strategies for low literacy interventions in T2DM have found improvement in HbA1c of up to 1.5% and the strategies used there should help inform the development of courses for similarly-placed people with T1DM (Scoyoc and DeWalt, 2010).

Once there was provision of SE courses to meet the needs of all groups identified, an inclusive, yet tailored, marketing strategy can be deployed. As previously discussed (in 15.3), this will need to include targeting the harder to reach groups, who were more likely not to attend SE or even specialist care. The influential role of HCPs would be maximised, as they would be able to offer SE, knowing that there was provision for all. Peer marketing and support strategies may also be of value, via social norming of attendance and allaying fears associated with judgement for 'poor control'. I have begun implementing a peer marketing model within our local diabetes clinic, specifically targeting the 'not yetter' group. This DAFNE champion project is based on the success of community diabetes champions, but evaluates the effectiveness of peer-marketing in T1DM and is not offering wider peer support (Shen et al., 2015).

The study design has ensured my research findings are generalisable to a wider population, both geographically and within other LTCs. The use of mixed methods has provided both a broad and deep understanding of this complex issue. The lengths taken to include the 'harder to reach' populations have reduced survey response bias, providing insight into factors associated with health inequalities. The evidence for T1DM has thus far relied on small numbers of case studies, and anecdotal evidence, or direct translation from T2DM studies. My study is the first to use a large cohort to examine the barriers and potential interventions robustly. Its findings are supported by previous research in T2DM and national investigations into diabetes education, conducted by government bodies and the third sector (All Party Parliamentary Group on Diabetes, 2015, Wenzel, 2016, Winkley et al., 2015). Additionally, the barriers and interventions identified by my study are compatible with current theories for supporting people in engaging in healthy practices, as exemplified in the COM-B behaviour change wheel of Michie and colleagues, confirming the comprehensive understanding of the issues gained by my research strategy (Michie et al., 2011). In the current political climate, where focus is on self-management and reducing the gaps identified in the five year forward view, my findings are critical and dissemination of my results to as great an audience as possible is essential (Stevens, 2014).

My immediate plans for dissemination include production of an executive summary, particularly communicating the findings to commissioners and providers, which will be available on the Health Innovation Network (HIN) and CLAHRC websites. This will be accompanied by a media strategy from both organisations. Alongside this, I will publish my findings in high-impact peer review journals and harness social media to advertise publications in print. I will present my findings in local and national meetings; for example, at the annual diabetes professional conference in March 2017. Finally, I am already working with an on-going NIHR funded programme of research to improve the current DAFNE offering. This programme is focussing on adjusting the existing DAFNE curriculum to help participants maintain the learning in their daily lives and maintain more the initial benefits provided by the courses longer-term. My work will provide the basis for ensuring that a much larger proportion of adults with T1DM are able to benefit from such initiatives.

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19 Appendix

Type	Title	Start Date	End Date	Internal/ External	Length(Days)
Other Development Activity	All Party Parliamentary group - diabetes education	10-Sep-14	10-Sep-14	External	2
Training Course	NATCEN - introduction to qualitative research	17-Sep-14	17-Sep-14	External	1
Training Course	Starting Your PhD in the Sciences	21-Oct-14	21-Oct-14	External	
Posters	Primary Care diabetes	20-Nov-14	20-Nov-14	External	1
Training Course	Writing A Literature Review	10-Dec-14	10-Dec-14	External	
Training Course	SPSS Introduction	15-Jan-15	15-Jan-15	External	
Training Course	Advanced Qualitative research skills	26-Jan-15	24-Feb-15	Internal	6
Other Talks / Presentations	Medical student teaching	13-Oct-14	23-Mar-15	Internal	5
Training Course	Microsoft Excel intermediate	31-Mar-15	31-Mar-15	External	
Training Course	SPSS intermediate	27-Apr-15	27-Apr-15	External	
Other Talks / Presentations	Producing a toolkit - Belfast	29-Apr-15	29-Apr-15	External	1
Posters	Diabetes and Nutritional Sciences department PhD	06-May-15	06-May-15	Internal	0.5
Training Course	Implementation Science Masterclass	01-Jun-15	02-Jun-15	Internal	2
Training Course	Social Return on Investment - nef	24-Jun-15	25-Jun-15	External	2
Training Course	Unconscious Bias	03-Aug-15	03-Aug-15	Internal	0.5

Training Course	Correlation and Linear regression models	13-Oct-15	13-Oct-15	External	0.5
Training Course	Regression Model	04-Nov-15	04-Nov-15	External	0.5
Conference Presentation	Diabetes Professional Care	11-Nov-15	12-Nov-15	External	2
Training Course	Specialty Lead Registrar	04-Dec-15	04-Dec-15	Internal	1
Other Talks / Presentations	Medical student teaching - diabetes; MBBS yr 3 & 5	01-Sep-15	14-Dec-15	Internal	3
Training Course	Learning to use NVivo	30-Jan-16	30-Jan-16	External	
Training Course	Microsoft Word long documents for theses	16-Feb-16	16-Feb-16	External	
Posters	Diabetes UK annual professional conference	01-Mar-16	04-Mar-16	External	4
Other Talks / Presentations	South East Thames Diabetes Physician Meeting	06-May-16	06-May-16	External	0.5
Other Talks / Presentations	DAFNE plus group	10-May-16	10-May-16	External	0.5
Seminars	North European Young Diabetologists meeting	18-May-16	20-May-16	External	3
Training Course	RAND evaluation training	12-Jun-16	12-Jun-16	External	1
Training Course	South West Systems Leading Across Boundaries	01-Jul-16	23-Nov-16	External	10
Seminars	European Association for Study of Diabetes 2016	11-Sep-16	09-Dec-16	External	4
Training Course	Managing across boundaries	10-Jun-16	18-Dec-16	External	5

19.1.14 Appendix A: Training and courses attending from 2014-2017

19.1.15 Appendix B: Search terms used to identify relevant articled in databases for literature review.

EMBASE classic + EMBASE search 23rd October 2015

	Search term	Result
1	Health literacy/	4127
2	Numeracy.mp	933
3	(health and literacy).mp	9953
4	"rapid estimate of health literacy".mp	1
5	"test of functional health literacy".mp	368
6	"Hebrew health literacy test".mp	1
7	"newest vital signs".mp	5
8	"short assessment of health literacy".mp	15
9	"wide range achievement test".mp	439
10	"nutritional literacy".mp	8
11	"literacy assessment for diabetes".mp	5
12	"single item numeracy screener".mp	0
13	"demographic assessment".mp	39
14	"brief estimate".mp	8
15	"diabetes numeracy".mp	19
16	"medical data interpretation".mp	7
17	"subjective numeracy".mp	41
18	"numeracy test".mp	36
19	(diabet$ adj2 litera$).mp	482
20	(diabet$ adj2 numera$).mp	37
21	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20	11332
22	Exp insulin dependent diabetes mellitus	86036
23	"insulin-depend$ diabet$" or "insulin depend$ diabet$" or "insulindepend$ diabet$".mp	238917
24	"type 1 diabet$" or "type1 diabet$" or "type-1 diabet$".mp	44888
25	"type I diabet$" or "typeI diabet$" or "type-I diabet$"	7964
26	Child adj2 diabet$.mp	742
27	Acidos$ adj2 diabet$.mp	1300
28	Labil$ adj2 diabet$.mp	203
29	Keto$ adj2 diabet$.mp	11018
30	Juvenile$ adj2 diabet$.mp	5423
31	Autoimmune$ adj2 diabet$.mp	4409
32	(Auto and immune$) adj2 diabet$.mp	302
33	(Sudden and onset) adj2 diabet$.mp	194
34	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33	260979
35	21 and 34	446
36	Limit 35 to (human and English language and (adult 18-64 years or aged 65+ years)	210

HMIC search on 23rd October 2015

	Search term	Result
1	Exp health literacy/	144
2	Exp numeracy/	38
3	(health and literacy).mp	413
4	"rapid estimate of health literacy".mp	0
5	"test of functional health literacy".mp	7

6	“Hebrew health literacy test”.mp	0
7	“newest vital signs”.mp	0
8	“short assessment of health literacy”.mp	0
9	“wide range achievement test”.mp	4
10	“nutritional literacy”.mp	0
11	“literacy assessment for diabetes”.mp	0
12	“single item numeracy screener”.mp	0
13	“demographic assessment”.mp	0
14	“brief estimate”.mp	0
15	“diabetes numeracy”.mp	0
16	“medical data interpretation”.mp	0
17	“subjective numeracy”.mp	0
18	“numeracy test”.mp	5
19	(diabet$ adj2 litera$).mp	6
20	(diabet$ adj2 numera$).mp	0
21	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20	452
22	Diabetes/	2704
23	“insulin-depend$ diabet$” or “insulin depend$ diabet$” or “insulindepend$ diabet$”.mp	86
24	“type 1 diabet$” or “type1 diabet$” or “type-1 diabet$”.mp	155
25	“type I diabet$” or “typeI diabet$” or “type-I diabet$”	3
26	Child adj2 diabet$.mp	3
27	Acidos$ adj2 diabet$.mp	1
28	Labil$ adj2 diabet$.mp	0
29	Keto$ adj2 diabet$.mp	7
30	Juvenile$ adj2 diabet$.mp	4
31	Autoimmune$ adj2 diabet$.mp	3
32	(Auto and immune$) adj2 diabet$.mp	1
33	(Sudden and onset) adj2 diabet$.mp	0
34	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33	2745
35	21 and 34	20

PsychINFO search on 23rd October 2015

	Search term	**Result**
1	health literacy/	1549
2	Mathematical ability/	5469
3	(health and literacy).mp	3855
4	“rapid estimate of health literacy”.mp	0
5	“test of functional health literacy”.mp	367
6	“Hebrew health literacy test”.mp	1
7	“newest vital signs”.mp	4
8	“short assessment of health literacy”.mp	20
9	“wide range achievement test”.mp	3522
10	“nutritional literacy”.mp	4
11	“literacy assessment for diabetes”.mp	4
12	“single item numeracy screener”.mp	0
13	“demographic assessment”.mp	25
14	“brief estimate”.mp	3
15	“diabetes numeracy”.mp	9
16	“medical data interpretation”.mp	6
17	“subjective numeracy”.mp	61
18	“numeracy test”.mp	92

19	(diabet$ adj2 litera$).mp	86
20	(diabet$ adj2 numera$).mp	10
21	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20	12828
22	Exp Diabetes mellitus/	4334
23	“insulin-depend$ diabet$” or “insulin depend$ diabet$” or “insulindepend$ diabet$”.mp	949
24	“type 1 diabet$” or “type1 diabet$” or “type-1 diabet$”.mp	1404
25	“type I diabet$” or “typeI diabet$” or “type-I diabet$”	295
26	Child adj2 diabet$.mp	113
27	Acidos$ adj2 diabet$.mp	11
28	Labil$ adj2 diabet$.mp	1
29	Keto$ adj2 diabet$.mp	129
30	Juvenile$ adj2 diabet$.mp	181
31	Autoimmune$ adj2 diabet$.mp	17
32	(Auto and immune$) adj2 diabet$.mp	0
33	(Sudden and onset) adj2 diabet$.mp	7
34	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33	5973
35	21 and 34	64
36	Limit 35 to (human and English language and adulthood <18+ years>	41

MEDLINE search 23rd October 2015

	Search term	**Result**
1	Health literacy/	2412
2	Educational status/	43336
3	Numeracy.mp	742
4	(health and literacy).mp	8612
5	“rapid estimate of health literacy”.mp	1
6	“test of functional health literacy”.mp	272
7	“Hebrew health literacy test”.mp	1
8	“newest vital signs”.mp	2
9	“short assessment of health literacy”.mp	9
10	“wide range achievement test”.mp	303
11	“nutritional literacy”.mp	7
12	“literacy assessment for diabetes”.mp	2
13	“single item numeracy screener”.mp	0
14	“demographic assessment”.mp	33
15	“brief estimate”.mp	3
16	“diabetes numeracy”.mp	10
17	“medical data interpretation”.mp	8
18	“subjective numeracy”.mp	28
19	“numeracy test”.mp	29
20	(diabet$ adj2 litera$).mp	339
21	(diabet$ adj2 numera$).mp	19
22	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21	51194
23	Diabetes mellitus/ or diabetes mellitus, type 1/ or diabetic ketoacidosis	158926
24	“insulin-depend$ diabet$” or “insulin depend$ diabet$” or “insulindepend$ diabet$”.mp	24978
25	“type 1 diabet$” or “type1 diabet$” or “type-1 diabet$”.mp	30464

26	“type I diabet$” or “typeI diabet$” or “type-I diabet$”	5885
27	Child adj2 diabet$.mp	497
28	Acidos$ adj2 diabet$.mp	786
29	Labil$ adj2 diabet$.mp	96
30	Keto$ adj2 diabet$.mp	7117
31	Juvenile$ adj2 diabet$.mp	2780
32	Autoimmune$ adj2 diabet$.mp	3483
33	Auto and (immune$ adj2 diabet$).mp	164
34	Sudden and (onset adj2 diabet$).mp	122
35	23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34	183481
36	22 and 35	1046
37	Limit 37 to English language and humans and (“young adult (19 to 24 years)” or “adult (19 to 44 years)” or “young adult and adult (19-24 and 24-44)” or “middle age (45 to 64 years)” or “middle aged (45 plus years)” or “all aged (65 and over)” or “aged (80 and over)”)	701

Reference	Included?	Inclusion Criteria	Contact with author
Anonymous (2008) Summaries for patients. Association of numeracy and diabetes control. Annals of internal medicine 148: I53	No	Unavailable	
Anonymous (2013) Singapore Health and Biomedical Congress, SHBC 2013. Annals of the Academy of Medicine Singapore Conference: Singapore Health and Biomedical Congress, SHBC 42	No	Not available in library or inter-library loan	
Abdulazeez MA, Busari AI, Yakubu S, Anigo KM, Idris HO, Salihu A (2013) Prevalence of hypertension and impaired renal function in diabetic patients attending ahmadu bello university Teaching Hospital (Abuth), Shika, Zaria, Kaduna State, Nigeria. Journal of Medical Sciences (Faisalabad) 13: 346-352	No	No health literacy/numeracy measure 36% T1DM	
Arifulla M, John LJ, Sreedharan J, Muttappallymyalil J, Basha SA (2014) Patients' adherence to anti-diabetic medications in a Hospital at Ajman, UAE. Malaysian Journal of Medical Sciences 21: 44-49	No	T2DM	
Bahru Y, Abdulkadir J (1993) Assessment of diabetes education in the teaching hospital, Addis Ababa, Ethiopia. Diabetic Medicine 10: 870-873	No	No health literacy/numeracy measure	
Bains S, Osborn CY, Egede LE (2010) Demographic proxies predict diabetes self-care behaviors above and beyond health literacy. Journal of Investigative Medicine 58 (2): 386	No	T2DM - not specified in methods, but in discussion	
Barnard K, Parkin C, Young A, Ashraf M (2012) Use of an automated bolus calculator reduces fear of hypoglycemia and improves confidence in dosage accuracy in patients with type 1 diabetes mellitus treated with multiple daily insulin injections. Journal of Diabetes Science & Technology 6: 144-149	No	No health literacy/numeracy measure	
Baz L, Muller N, Beluchin E, et al. (2012) Differences in the quality of diabetes care caused by social inequalities disappear after treatment and education in a tertiary care centre. Diabetic medicine : a journal of the British Diabetic Association 29: 640-645	No	No health literacy/num	

		eracy measure	
Beggan MP, Cregan D, Drury MI (1982) Assessment of the outcome of an educational programme of diabetes self-care. Diabetologia 23: 246-251	No	No health literacy/numeracy measure Children/adolescents	
Bella AF (1992) A prospective study of insulin-dependent diabetic Nigerian Africans. Journal of the National Medical Association 84: 126-128	No	No health literacy/numeracy measure	
Bergers J, Nijhuis F, Janssen M, van der Horst F (1999) Employment careers of young type I diabetic patients in The Netherlands. J Occup Environ Med 41: 1005-1010	No	No health literacy/numeracy measure	
Bernal H, Wooley S, Schensul JJ (1997) The challenge of using Likert-type scales with low-literate ethnic populations. Nursing research 46: 179-181	No	Feasibility/score design study No diabetes outcomes	
Beverly EA, Ganda OP, Ritholz MD, et al. (2012) Look who's (not) talking: diabetic patients' willingness to discuss self-care with physicians. Diabetes Care 35: 1466-1472	No	No health literacy/numeracy measure	
Bhargava A, Wartak SA, Friderici J, Rothberg MB (2014) The impact of Hispanic ethnicity on knowledge and behavior among patients with diabetes. The Diabetes educator 40: 336-343	No	No health literacy/numeracy measure Unclear if T2/T1	

Buysse HE, de Moor GJ, de Maeseneer J (2013) Introducing a telemonitoring platform for diabetic patients in primary care: will it increase the socio-digital divide? Primary care diabetes 7: 119-127	No	No health literacy/numeracy measure	
Campos-Barrera E, Duran-Perez EG, Almedavaldes P, Mehta R, Cuevas-Ramos D, Gomezperez FJ (2011) Impact of diabetes-related numeracy, diabetes self-care activities and depression on metabolic control in patients with type 1 diabetes mellitus. Diabetes 60	Yes	Conference abstract so insufficient detail	Email x2 to author 30/3/16 – no reply
Cavanaugh K, Huizinga MM, Wallston KA, et al. (2008) Association of numeracy and diabetes control. [Summary for patients in Ann Intern Med. 2008 May 20;148(10):I53; PMID: 18490670]. Annals of Internal Medicine 148: 737-746	Yes	T1DM & T2DM mixed	Communication with R. Rothmann to recommend further 24/2/15
Chaturvedi N, Stephenson JM, Fuller JH (1996) The relationship between socioeconomic status and diabetes control and complications in the EURODIAB IDDM Complications Study. Diabetes Care 19: 423-430	No	No health literacy/numeracy measure	
Erkkola M, Salmenhaara M, Kronberg-Kippila C, et al. (2010) Determinants of breast-feeding in a Finnish birth cohort. Public Health Nutr 13: 504-513	No	Risk of T1DM (not actually T1DM)	
Ford S, Mai F, Manson A, Rukin N, Dunne F (2000) Diabetes knowledge--are patients getting the message? Int J Clin Pract 54: 535-536	No	No measure of self-care Type of diabetes not specified	
Goldsmith D, Anis M, Dieguez Otero K, Hasan SA (2012) Influence of health literacy on diabetes mellitus outcomes. Journal of General Internal Medicine 27: S229	No	Conference abstract – mixed population, no further	No response to email. (29/2/15)

		data re: proportions/individual T1DM	
Ismail IS, Nazaimoon WM, Mohamad WB, et al. (2000) Sociodemographic determinants of glycaemic control in young diabetic patients in peninsular Malaysia. Diabetes Research & Clinical Practice 47: 57-69	No	No health literacy/numeracy measure T2DM	
Jabbar A, Contractor Z, Ebrahim MA, Mahmood K (2001) Standard of knowledge about their disease among patients with diabetes in Karachi, Pakistan. Jpma The Journal of the Pakistan Medical Association. 51: 216-218	No	T2DM	
Japiassu LM, Brito GNO, Castro SH, Gomes MB (2015) A comparison of the neurobehavioral profile of type 1 and type 2 diabetes patients. Diabetes 64: A231	No	No 2nd outcome	
Kiani J, Moghimbeigi A, Azizkhani H, Kosarifard S (2013) The prevalence and associated risk factors of peripheral diabetic neuropathy in Hamedan, Iran. Archives of Iranian Medicine 16: 17-19	No	No health literacy/numeracy measure	
Klupa T, Matejko B, Kiec-Wilk B, Malecki MT (2013) Factors affecting glycaemic control in adult type 1 diabetic patients treated with personal insulin pumps. Diabetologia 56: S443	No	No health literacy/numeracy measure	
Lui CW, Dower J, Donald M, Coll JR (2012) Patterns and determinants of complementary and alternative medicine practitioner use among adults with diabetes in Queensland, Australia. Evidence-based Complementary and Alternative Medicine	No	No health literacy/numeracy measure	
Marks GR (2002) Relationships between diabetes knowledge, beliefs, perceived health competence, personality, and diabetes-related outcomes in adults with type I diabetes. Dissertation Abstracts International: Section B: The Sciences and Engineering 62: 5971	No	Unable to get article from library	No response to email. No

			published results available with search of author.
Mancuso J (2010) Impact of health literacy and patient trust on glycemic control in an urban USA population. Nursing and Health Sciences 12: 94 - 104	No	3.9% T1DM	Contacted for further details but email box full
Marden S, Thomas PW, Sheppard ZA, Knott J, Lueddeke J, Kerr D (2012) Poor numeracy skills are associated with glycaemic control in Type1 diabetes. Diabetic Medicine 29: 662-669	Yes		Contacted D.Kerr for recommendation or new data (29/2/15)
Martinez-Huedo MA, Lopez de Andres A, Hernandez-Barrera V, Carrasco-Garrido P, Martinez Hernandez D, Jimenez-Garcia R (2012) Adherence to breast and cervical cancer screening in Spanish women with diabetes: Associated factors and trend between 2006 and 2010. Diabetes and Metabolism 38: 142-148	No	No health literacy/numeracy measure	
Mbaezue N, Mayberry R, Gazmararian J, Quarshie A, Ivonye C, Heisler M (2010) The impact of health literacy on self-monitoring of blood glucose in patients with diabetes receiving care in an inner-city hospital. Journal of the National Medical Association 102: 5-9	No	Unclear proportion T1DM	Contacted to separate out T1 or details regarding proportion, no further details available.

Moore PA, Weyant RJ, Mongelluzzo MB, et al. (1998) Type 1 diabetes mellitus and oral health: assessment of tooth loss and edentulism. J Public Health Dent 58: 135-142	No	No health literacy/numeracy measure	
Moussa M, Sherrod D, Choi J (2013) An e-health intervention for increasing diabetes knowledge in African Americans. International Journal of Nursing Practice 19: 36-43	No	T1DM & T2DM but high proportion T2DM (>78%) and unable to separate out	Contacted 29/2/15 – unable to separate data.
Nguyen HT, Kirk JK, Arcury TA, et al. (2013) Cognitive function is a risk for health literacy in older adults with diabetes. Diabetes research and clinical practice 101: 141-147	No	Type of diabetes not classified but likely T2DM according to authors (>92% diagnosed over age 35yr)	
Nicolucci A, Maione A, Franciosi M, et al. (2008) Quality of life and treatment satisfaction in adults with Type 1 diabetes: A comparison between continuous subcutaneous insulin infusion and multiple daily injections. Diabetic Medicine 25: 213-220	No	No health literacy or numeracy measure	
Ntiri W, Stewart M (2009) Transformative learning intervention: Effect on functional health literacy and diabetes knowledge in older African Americans. Gerontology & Geriatrics Education 30: 100-113	No	Type of diabetes not classified but likely T2DM (mean age 68yr)	Contacted to verify type of diabetes, but no reply (29/2/15)

Nurss JR, el-Kebbi IM, Gallina DL, et al. (1997) Diabetes in urban African Americans: functional health literacy of municipal hospital outpatients with diabetes. The Diabetes educator 23: 563-568	No	T2DM	
Osborn CY, Cavanaugh K, Wallston KA, Rothman RL (2010) Self-efficacy links health literacy and numeracy to glycemic control. Journal of health communication 15 Suppl 2: 146-158	No	Likely T2DM – ethnic minority, mean age 54y 62% on insulin	Communication with R. Rothmann 29/2/15
Otero LM, Zanetti ML, Ogrizio MD (2008) Knowledge of diabetic patients about their disease before and after implementing a diabetes education program. Revista Latino-Americana de Enfermagem 16: 231-237	No	2/52 T1DM No health literacy/numeracy measure	
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Piatt A, Valerio A, Nwankwo R, Lucas M, Funnell M (2014) Health literacy among insulin-taking African Americans: A need for tailored intervention in clinical practice. The Diabetes educator 40: 240-246	No	Mixed population - insufficient numbers T1DM	Correspondence with author

Riaz M, Basit A, Fawwad A, Ahmedani MY, Rizvi ZA (2014) Factors associated with non-adherence to Insulin in patients with Type-1 diabetes. Pakistan Journal of Medical Sciences 30: 233-239	No	Mean age 17.9y	
Rothman RL, DeWalt DA, Malone R, Persell SD (2004) Diabetes disease management program is more effective for patients with low literacy. Journal of Clinical Outcomes Management 11: 752-753	No	Review/Commentary T2DM	
Rubin DJ, Donnell-Jackson K, Jhingan R, Golden SH, Paranjape A (2014) Early readmission among patients with diabetes: a qualitative assessment of contributing factors. Journal of Diabetes & its Complications 28: 869-873	No	No health literacy/numeracy measure	
Schillinger D, Barton LR, Karter AJ, Wang F, Adler N (2006) Does literacy mediate the relationship between education and health outcomes? A study of a low-income population with diabetes. Public Health Reports 121: 245-254	No	T2DM	Contacted to recommend others – no recommendation
Stiles E (2011) Promoting health literacy in patients with diabetes	No	Literature review	
Subramanian U, Hofer T, Klamerus M, Zikmund-Fisher B, Heisler M, Kerr E (2007) Knowledge of blood pressure targets among patients with diabetes. Primary Care Diabetes 1: 195-198	No	No health literacy/numeracy measure Population likely T2DM (not specified) – age 68.9y with duration DM 12.6yr	
Tenforde M, Nowacki A, Jain A, Hickner J (2012) The association between personal health record use and diabetes quality measures. Journal of General Internal Medicine 27: 420-424	No	Type of diabetes not specified	

		No health literacy/numeracy measure	
Trief PM, Cibula D, Rodriguez E, Akel B, Weinstock RS (2016) Incorrect Insulin Administration: A Problem That Warrants Attention. Clinical Diabetes 34: 25-33	No	Mixed population - insufficient numbers of T1DM	
Trief PM, Izquierdo R, Eimicke JP, et al. (2013) Adherence to diabetes self care for white, African-American and Hispanic American telemedicine participants: 5 year results from the IDEATel project. Ethnicity & Health 18: 83-96	No	T2DM	
van der Heide I, Uiters E, Rademakers J, Struijs JN, Schuit AJ, Baan CA (2014) Associations among health literacy, diabetes knowledge, and self-management behavior in adults with diabetes: results of a dutch cross-sectional study. Journal of health communication 19 Suppl 2: 115-131	No	Predominantly T2DM	No response to email request for further data.
Veghari GR, Marjani A, Joshaghani H (2007) The study of diabetes mellitus in Gorgan, Iran. Saudi Medical Journal 28: 1300-1301	No	T2DM >70% No health literacy or numeracy measure	
Walker RJ, Smalls BL, Hernandez-Tejada MA, Campbell JA, Egede LE (2014) Effect of diabetes self-efficacy on glycemic control, medication adherence, self-care behaviors, and quality of life in a predominantly low-income, minority population. Ethnicity and Disease 24: 349-355	No	T2DM	
Wallace AS, Carlson JR, Malone RM, Joyner J, Dewalt DA (2010) The influence of literacy on patient-reported experiences of diabetes self-management support. Nursing Research 59: 356-363	No	T2DM	
Weltermann BM, Driouach-Bleckmann Y, Reinders S, Berndt P, Gesenhues S (2013) Stroke knowledge among diabetics: A cross-sectional study on the influence of age, gender, education, and migration status. BMC Neurology Vol 13 Dec 2013, ArtID 202 13	No	T2DM	

White RO, Eden S, Wallston KA, et al. (2015) Health communication, self-care, and treatment satisfaction among low-income diabetes patients in a public health setting. Patient education and counseling 98: 144-149	No	T2DM only	
Yan J, Liu Y, Zhou B, Sun M (2014) Pre-hospital delay in patients with diabetic foot problems: Influencing factors and subsequent quality of care. Diabetic Medicine 31: 624-629	No	2% T1DM – not separated out No health literacy or numeracy measure	
Yekta Z, Pourali R, Aghassi MR, Ashragh N, Ravanyar L, Pour MYR (2011) Assessment of self-care practice and its associated factors among diabetic patients in urban area of urmia, northwest of iran. Journal of Research in Health Sciences 1: 33-38	No	T2DM	
Yun LS, Hassan Y, Aziz NA, Awaisu A, Ghazali R (2007) A comparison of knowledge of diabetes mellitus between patients with diabetes and healthy adults: A survey from north Malaysia. Patient education and counseling 69: 47-54	No	No secondary outcome Likely T2DM population but not specified	
Zhang XH, Wee HL, Tan K, Thumboo J, Li SC (2009) Is diabetes knowledge associated with health-related quality of life among subjects with diabetes? A preliminary cross-sectional convenience-sampling survey study among English-speaking diabetic subjects in Singapore. Journal of Chinese Clinical Medicine 4: 144-150	No	33% T1DM No diabetes endpoint (measured Quality of Life)	
Zaugg SD, Dogbey G, Collins K, et al. (2014) Diabetes numeracy and blood glucose control: Association with type of diabetes and source of care. Clinical Diabetes 32: 152-157	Yes		Contacted & suggested Vanderbilt group.

19.1.16 Appendix C: Table of reasons for inclusion or exclusion of articles in literature review where full text was reviewed.

19.1.17 Appendix D: Retinal screening data sharing agreement letter

National Screening Programme for Diabetic Retinopathy NHS

What sort of information about me is held by the NHS DR Screening programme?

The only information that the programme will have about you at the beginning will be your name, date of birth, contact details, NHS number, details of your GP, information to help establish your preferred language and contact method and whether you might need large print documents and the fact that you have been diagnosed as having Type 1 or Type 2 diabetes.

Once you agree to have your eyes screened then it will be necessary to be able to check on the results on any previous screening event. It might be that the programme would like to have further information about your medical history relating to your diabetes (such as your blood sugar levels, blood pressure, foot checks, smoking history etc, but not sensitive information such as erectile dysfunction) so that those who are assessing you have a more complete picture about what is happening. When you confirm or attend your screening appointment it will be taken that you are consenting for that sort of data to be given to those involved in screening and assessment both in the programme and in the acute trust. However if you do not wish this further information to pass to the programme then you should let the programme staff or your GP know. This will not prevent your eyes being screened but would mean that staff are less able to assess your case as carefully. You can change your mind about this at any time.

Who will see information about me?

Those involved in the **administration** of the programme (normally based in a Primary Care Trust or a hospital): the details can be found on the letter accompanying this document.

Those who are carrying out the **screening process** (including putting in the eye drops, checking vision, taking your history, taking photographs of your eyes and grading the photographs). These are either staff employed by the PCT, acute trust or other NHS body OR are optometrists, self-employed ophthalmologists or staff employed by independent companies. The programme will provide you with a list of non-NHS personnel and companies if you are concerned in any way about who will see information about you and you should let the programme staff know if you have any particular concerns about any particular individual or company.

If your case is referred to the **hospital** for further assessment the information about you will be forwarded to the hospital so that those who will be looking after your case can have as much information about your history as possible.

In order to make sure that the programme is operating effectively from time to time its work is assessed by **clinical auditors** and others involved in **quality assurance**. They may need to have access to your data. In addition efforts will be made nationally to carry out research using fully anonymised data to try and identify as precisely as possible how best diabetes should be managed in the long term (some examples may be how many people have diabetic retinopathy in any area or how quickly it progresses in different groups of people). Any efforts to use any identifiable information would result in us working with the Patient Information Advisory Group to make sure that all necessary agreements are obtained.

Occasionally problems may occur in the software which is necessary to support the programme. Normally the software supplier will not need to see any information that is identified to a specific individual, but occasionally it may become necessary to supply basic information to ensure that the correct information is maintained by the programme securely. Software suppliers who work with the NHS are bound by requirements of confidentiality and should be supervised by NHS staff if they need to look at information that is linked to a named individual.

Your results and screening information will be sent to your GP.

Guy's and St Thomas' NHS Foundation Trust
King's College Hospital NHS Foundation Trust

The BUDiE Study
Diabetes Research Group
King's College London
Weston Education Centre
10 Cutcombe Road
London
SE5 9RJ
tel: 0207 848 5670
email: kch-tr.BUDiE@nhs.net
www.budie.org

[Insert date]

[Insert invitee address]

Your unique study number: [unique study #]

The BUDiE study (Barriers to Uptake of Diabetes Education)

Dear [Insert name]

A local project, being run by King's College London needs your help. The project wants to make accessing courses about living with type 1 diabetes easier. You should have received an information leaflet and survey a few days ago, please fill this in and return it or contact Dr Sophie Harris for more information. You get £5 for returning a completed survey!

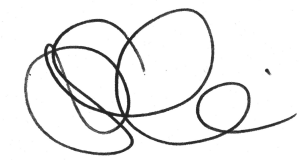
This is what one of our participants said:

> *"I learnt more in five days about my diabetes than I had been told in clinic within 16 years. Things around what to do when unwell to stop my sugar levels going too high, what to do before travelling, driving or doing exercise, and most importantly drinking alcohol with friends. I also met some other people with diabetes, which gave me some great tips on how to talk to my family, friends, work and loved ones about my diabetes and made me realise I wasn't the only one struggling at times. There is a lot to think about managing my diabetes day to day, but taking a course gave me, and lots of other people, the confidence to achieve the things I want in life. However, there are still a lot of people that don't have access to this course and*

we could really benefit from your views and ideas on how to make the course better and easier for you and others to attend. Together, with your views, we could help to change the lives of people with diabetes in Lambeth and Southwark, so that they can achieve all the things they want to."

Alex, Type 1 diabetes for 25 years

Thank you for your help,



Dr Sophie Harris
Diabetes Researcher

-

19.1.19 Appendix F: Patient information sheet

Thank you for taking time to read the information. We hope you will consider participating in the BUDiE Study.

For more information, contact Dr Sophie Harris
Diabetes Research Team
King's College London
Weston Education Centre
10 Cutcombe Road
London SE5 9RJ

tel: 0207 848 5670
email: kch-tr.BUDiE@nhs.net
www.budie.org

Having trouble reading this?
Call 0207 848 5670 **for help.**

The BUDiE Study

Barriers to Uptake of Diabetes Education

Do you have type 1 diabetes?

Do you live in Southwark or Lambeth?

If so, you can help us develop services for people like you.

PIS survey V6; 15/01/15
Project #: 14/LO/1751
Produced by the BUDiE Study team, January 2015

Health Innovation Network South London

KING'S HEALTH PARTNERS

Guy's and St Thomas' NHS Foundation Trust
King's College Hospital NHS Foundation Trust

NHS
National Institute for Health Research

Will you take part in our research to help improve support for adults who have type 1 diabetes?

About the BUDiE Study
We are a team of diabetes researchers at King's College London. We know that managing diabetes every day is hard work. You spend many hours making decisions about your care – from what to eat to how much insulin to inject.

Self-management courses that teach people more about their diabetes health can help take the mystery out of the highs and lows. But only 30 per cent of people who have type 1 diabetes in Southwark and Lambeth have been on one of these courses. We want to find out WHY so that we can improve our service to better meet your needs.

How will we do this?
We are gathering opinions via surveys and discussions. The survey takes the form of a simple questionnaire and we would like everyone who lives in Southwark and Lambeth who has type 1 diabetes to complete it. The survey is available online at **www.budie.org**, or you can fill in a paper version.

We are also looking for a smaller number of people to participate in more in-depth conversations and focus groups. A separate information leaflet is available if you are interested.

Will I be paid for my involvement?
To say thank you for taking the time to fill in the survey, we will give you a £5 gift voucher.

Advantages and disadvantages of participating
This study may not directly benefit you, but it does give you an opportunity to help improve services for people who have type 1 diabetes. It also gives you the chance to tell diabetes researchers your views.

We know your time is precious. The survey is divided into sections: the first two sections are essential and take 10 minutes to complete. The answers to the questions in the remaining sections are extremely useful to us. It will take a further 20 minutes for you to complete them.

Do I have to be involved?
No, you do not have to be involved. And if you agree to participate, you can change your mind at any time.

Will any information I give be kept confidential?
Yes, we follow ethical and legal guidelines. All information about you will be handled in confidence. See the opposite page for more details.

I want to fill in the BUDiE Study survey: what do I do?
You may have received this leaflet in the post along with a paper version of the survey. In which case, please fill in the questionnaire and return it to us, or visit www.budie.org and complete the questionnaire online.

If you have been given this leaflet in a diabetes clinic, please tell the person who gave it to you, or your diabetes healthcare professional, that you would like to complete the BUDiE Study survey.

Or simply visit www.budie.org and fill in the online survey there.

Additional information about the BUDiE Study

- This is an educational project funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) South London in collaboration with King's College London, King's College Hospital NHS Foundation Trust, Guy's and St Thomas' NHS Foundation Trust and the Health Innovation Network.
- This study has been reviewed and given favourable opinion by Dulwich Research Ethics Committee.
- Your decision about whether to participate in the BUDiE Study (or not) will not affect your usual diabetes care.
- You can withdraw from the study at any point. Information collected may still be used (with your consent).
- All personal information will be handled in confidence. You will be assigned a study number and any identifying information will be kept separately to maintain confidentiality.
- Data will be collected either online or via paper questionnaires. The research team will be responsible for this. The information will be analysed and stored securely on password-protected university computers.
- We will ask for your consent to contact you again in the future to inform you about further studies into diabetes.
- The information we collect for this study may be useful to support further diabetes research in the NHS. We will ask your consent to store it for a period of seven years. We will use professional, secure archiving services. After this time, data will be disposed of securely.
- While nhs.net email is secure, you should be aware that your email address and online survey is not. We therefore substitute your name for a study number for the online survey to minimise risk.
- The survey contains questions about your mental health and wellbeing. If your answers indicate you may be experiencing mental health problems, we will discuss these issues with you and your GP if we think it is clinically appropriate to do so.
- Local GPs and diabetes teams are aware of the study. With your consent, we will contact them to get recent blood results and other diabetes related information. However, we will not share your responses with them because we want you to be able to talk openly and honestly about your experiences.
- To qualify for a £5 gift voucher, you must complete at least the first two sections of the survey.

If you would like any more information, or have questions, please contact Dr Sophie Harris, 020 7848 5670, kch-tr.BUDiE@nhs.net or visit **www.budie.org**

If you have concerns, or wish to complain formally, you can do this via the Patient Advice and Liaison Service: at King's College Hospital, 0203 299 3601, or at Guy's and St Thomas' Hospitals, 0207 188 8801.

19.1.20 Appendix G: Sample B (PWD) survey

The BUDiE Study

Barriers to Uptake of Diabetes Education

Do you have type 1 diabetes?

Do you live in Southwark or Lambeth?

If so, you can help us develop services for people like you.

The NHS provides free courses for people who have type 1 diabetes to help them understand more about, and better manage, their condition. Many people who have completed these courses say they feel more confident about dealing with their diabetes and have fewer highs and lows.

DAFNE is a five-day course run in Southwark and Lambeth. But most people with type 1 diabetes who live in these two boroughs do not go on it. We are a team of diabetes researchers who work at King's College London and we want to find out why this is the case.

The research is called the BUDiE (Barriers to Uptake of Diabetes Education) Study and is led by Dr Sophie Harris who is a diabetes researcher and doctor.

The study is financially supported by the National Institute for Health Research (NIHR) and the NHS.

Please help us by filling in this survey.

Contact Dr Sophie Harris by emailing kch-tr.BUDiE@nhs.net to find out more or visit www.budie.org

Patient survey v11 24/2/15 | Project # 14/LO/1751

produced by the BUDiE Study team, January 2015

The study is funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) South London in collaboration with King's College London, King's College Hospital NHS Foundation Trust, Guy's and St Thomas' NHS Foundation Trust and the Health Innovation Network.

NHS
National Institute for Health Research

Thank you very much for participating in our study

Please take your time to fill in this survey.
It is also available online at www.budie.org.
If you have already participated in the online survey then please do NOT complete the paper version.
Remember your personal details will be anonymised and all information treated in confidence.
If you want more information before starting, please contact us.

Best wishes,

Dr Sophie Harris

Diabetes Research team
King's College London
10 Cutcombe Road, SE5 9RJ
tel: 0207 848 5670

email: kch-tr.BUDiE@nhs.net

This page will be removed and stored separately from your survey.

CONTACT INFORMATION

Please use **BLOCK** capitals
To ensure that our records are up-to-date please provide the following information:

First name:

Surname:

Date of birth:

Preferred contact address:

Postcode:

Email:

Guidance for completing the survey:

1. Please work from the beginning, answering each question as best you can.
2. You should have a study number, either sent to you in a letter or given to you in clinic. If you don't have a study number you can still complete this survey either using your NHS number or leave this section blank.
3. The survey should take 10 - 30 minutes to complete.
4. The most important questions come first. Please return your survey to us even if you don't manage to complete it.
5. You qualify for a £5 gift voucher if you complete at least the first 2 sections. If you make it to the end - well done!
6. Please contact us if you would like help filling in the survey or need more information.

(Please be aware that email addresses cannot be completely secure and it is therefore advisable not to use email for personal/clinical details that you would want kept confidential)

Telephone numbers

Home:

Work:

Mobile:

This survey is just one part of the study and we will be carrying out in-depth conversations and focus groups to get to the bottom of what needs to be done to make self-management courses easier to attend.

I would like to find out more about the other parts of this study ☐

I am not interested in being involved in other parts of this study ☐

Terms used in the survey:

Self-management courses – These are courses that help you to better understand your diabetes. They may also be called education courses or programmes. The locally run one is called DAFNE. They usually teach you about carbohydrate counting and insulin dose adjustment. They also teach other skills to manage your blood sugar, such as when you are unwell or exercise. There are a few different courses but they usually bring 4-10 people with type 1 diabetes together. The course may run during the day/evening and may be just a few hours or a week long.

Diabetes nurse in hospital –specialist nurse working with people with diabetes in the hospital setting.

Diabetes nurse in community – specialist nurse who only deals with people with diabetes. These nurses work in community clinics like intermediate clinics and community hospitals, but may also visit your GP's surgery.

Practice nurse – nurse working in your GP's surgery. These nurses are trained to look after people with diabetes, as well as other chronic illnesses like asthma or heart disease.

Diabetes doctor in community – doctor who specialises in diabetes, and works in the hospital but also runs clinics in the community, either community hospitals or GP surgery clinics.

SECTION 1 – Self-management courses

This section asks for your experiences of self-management courses for adults with type 1 diabetes. It doesn't matter if you have never heard of any self-management courses or if you have completed lots of courses. We want to hear your opinions. By telling us what you really think about the courses

Your study number:

Today's date:

1. Please indicate which type of diabetes you have?

Type 1[1] ☐
Type 2[2] (please go to page 21) ☐
Not sure[3] (*we may contact you to discuss further*, for now please go to Q2) ☐
I don't have diabetes[0] (go to page 21) ☐

2. How long have you lived with type 1 diabetes? Years Months

3. Have you ever COMPLETED a diabetes self-management course e.g. DAFNE/BERTIE?

No[1] (go to Q6) ☐
Yes[2] ☐

4. Was your course called DAFNE?

No[1] ☐
Yes[2] (go to Q8) ☐

5. You have told us that you have completed a diabetes self-management course that was not DAFNE. What was the course called?

(If you don't remember, use the space opposite to tell us the details – how many days/hours, did you have a curriculum, how long ago was it, number of other patients, who taught it).

(Next go to Q8)

6. Have you ever ATTENDED but NOT completed a self-management course?

No[1] ☐
Yes[2] (go to Q8) ☐

7. Has it ever been suggested that you attend a self-management course, but you haven't yet done one?

No[1] (go to Q12) ☐
Yes[2] (go to Q12) ☐

8. Ideally people should be referred to a self-management course within 9 months of being diagnosed with diabetes. Did this happen for you?

Unsure/Can't remember[0] ☐
No[1] ☐
Yes[2] ☐

9. Once you and your healthcare professional had agreed that you should attend a self-management course, did you have to wait more than 3 months for a space on the course?

Unsure/Can't remember[0] ☐
No[1] (go to Q14) ☐
Yes[2] ☐

10. Why did you have to wait more than 3 months to attend the course?

The course waiting list was more than 3 months[1] (go to Q14) ☐
I needed to organise my daily duties to free time to allow me to attend[2] (go to Q14) ☐
Not applicable, I didn't attend[3] (go to Q14) ☐
I wasn't personally ready and needed time to prepare myself [4] ☐
I don't know[5] (go to Q14) ☐
Other[6] (go to Q14) ☐

(*Please specify)*……..……..

11. You have indicated that you were not personally ready to attend a self-management course.

*Use the space opposite to tell us **who, how or what** helped you prepare to attend.*

(Next go to Q14)

12. Before you read about this study, had you ever heard of self-management courses run for people with diabetes?

No[1] (go to Q14) ☐
Yes[2] ☐

13. Where did you hear about these courses? *(select **all** relevant options)*

Other patients[1] ☐
My GP[2] ☐
Practice nurse[3] ☐
Dietitian[4] ☐
Clinical psychologist/Psychiatrist[5] ☐
Diabetes nurse in the community[6] ☐
Diabetes nurse in hospital[7] ☐
Diabetes doctor[8] ☐
Diabetes UK[9] ☐
Diabetes Research & Wellness Foundation[10] ☐
Information leaflet[11] ☐
Website[12] ☐
Other[13] ☐

(*Please specify*)……

14. DAFNE (Dose Adjustment For Normal Eating) is the self-management course that Southwark and Lambeth runs for people with type 1 diabetes. It is a self-management course that is held over 5 days, from 9am-5pm each day. It is held in groups of around 6-10 people with type 1 diabetes, led by a dietitian and diabetes nurse. It is intended to teach you how to adjust your insulin treatment to live a flexible lifestyle, while getting the best possible diabetes control. It does this by teaching you to count carbohydrate portions and adjust your insulin accordingly. You need to inject insulin between 4-6 times per day and check your blood sugar before meals and before bed.

Please answer one of the two following sets of questions:

*If you have **NOT** attended DAFNE or a similar course answer part **A***

*If you **have** attended DAFNE or a similar course answer part **B***

PART A - Fill this part in if you have NOT attended a self-management course

What do you think is the ONE biggest thing preventing you from coming to a self-management course? *Use the space opposite to answer*	
What do you think is the ONE biggest thing that would make it easier for you/encourage you to attend? *Use the space opposite to answer*	
Please use the space opposite to list other factors that you feel make it difficult/discourage you from using the DAFNE course	1. …… ……..

2. ……

……..

3. ……

……..

NOW go to **question 15**

PART B - Fill this part in if you have attended a self-management course

What was the ONE most important thing that encouraged you to attend DAFNE or similar self-management courses? *Use the space opposite to answer*	
Please list other factors that encouraged you to attend your DAFNE or similar courses *Use the space opposite to answer*	1. …… …….. 2. …… …….. 3. …… ……..

Use the space opposite to give us additional feedback or suggestions. We are particularly interested in hearing: 1. What made it difficult/discouraged you from attending 2. If you did not manage to complete the course, why this was. 3. If you had to wait a long time to attend the course, how long did you wait?	

One factor that may influence your joining DAFNE/similar courses would be how it was presented to you. The next questions ask about how you learned about self-management courses?

15. When was the last time a healthcare professional discussed self-management courses with you?

A week ago[1] ☐
A month ago[2] ☐
About 6 months ago[3] ☐
About 12 months ago[4] ☐
Not in the past year[5] ☐
Never[6] (go to Q18) ☐

---

16. Who began the conversation about self-management courses?

Can't remember/Unsure[0] ☐
Me[1] ☐
My healthcare professional[2] ☐
Not applicable[3] (go to Q18) ☐

---

17. How positive was your healthcare professional in advising you of the benefit of a diabetes self-management course? *(Please give a score 1-5)*

1	2	3	4	5
Not positive		Neutral		Extremely positive
☐	☐	☐	☐	☐

SECTION 2 – Reading and number skills

Self-management courses are usually taught in English and teach people to count carbohydrate portions and calculate insulin doses. We think some people may be put off because of this. The next few questions ask you what you think about your skills.

18. English is:

My first language[1] ☐
Not my first language but I am fluent/almost fluent[2] ☐
Not my first language but I can talk easily in English[3] ☐
Not my first language and I struggle day-to-day[4] ☐

19. What is your highest level of education completed?

Did not complete Primary school[1] ☐
Completed Primary school[2] ☐
Secondary school (i.e. GCSE/O-level or equivalent)[3] ☐
Completed secondary school (i.e. A-level or equivalent)[4] ☐
University[5] ☐
Other[6] ☐

(*Please specify*) ……

Other factors that may discourage people from attending self-management courses are competition for your time by other activities.

20. What is your employment status?

Employed[1] ☐
Self-employed[2] ☐
Unemployed[3] ☐
Studying[4] ☐
Caring (for child or adult)[5] ☐
Retired[6] ☐

21. Where do you go for advice regarding your diabetes health? *Select **all** that apply*

Other patients[1] ☐
My GP[2] ☐
Diabetes nurse in hospital[3] ☐
Diabetes doctor[4] ☐
Dietitian[5] ☐
Friends/family[6] ☐
Diabetes charities[7] ☐
Information leaflet[8] ☐
Website[9] ☐
Other[10] ☐

(please specify)……
…..

22. How confident are you filling in medical forms by yourself?

Not at all[0] ☐ A little bit[1] ☐ Somewhat[2] ☐ Quite a bit[3] ☐ Extremely[4] ☐

For the following questions please tick the box that best reflects how **good** you are at doing the following things:

	1 extremely good	2	3	4	5	6 not at all good
23. How good are you at working with fractions?	☐	☐	☐	☐	☐	☐
24. How good are you at working with percentages?	☐	☐	☐	☐	☐	☐
25. How good are you at working out a 15% tip?	☐	☐	☐	☐	☐	☐
26. How good are you at calculating how much a shirt will cost if it is 25% off?	☐	☐	☐	☐	☐	☐

For each of the following questions, please tick the box that **best reflects your answer:**

27. When reading the newspaper how HELPFUL do you find tables and graphs that are parts of the story?

1 Not at all helpful	2	3	4	5	6 Very helpful
☐	☐	☐	☐	☐	☐

28. When people tell you the chance of something happening do you prefer they use words ("it rarely happens") or numbers ("there's a 1% chance")?

1	2	3	4	5	6
☐	☐	☐	☐	☐	

Always prefer **words**					Always prefer **numbers**
☐					☐

29. When you hear a weather forecast, do you prefer predictions using percentages (e.g., "there will be a 20% chance of rain today") or predictions using only words (e.g., "there is a small chance of rain today")?

1	2	3	4	5	6
Always prefer **percentage**					Always prefer **words**
☐	☐	☐	☐	☐	☐

30. How often do you find numerical information to be useful?

1	2	3	4	5	6
Never					Very often
☐	☐	☐	☐	☐	☐

SECTION 3 – Are you confident in caring for yourself?

Research shows people's confidence improves after attending self-management courses, but it may be that some people don't attend these courses because they are already confident. In this section there are questions asking about your confidence in daily care activities and other things, like exercising.

After each of the following statements, tick the box that best indicates how much YOU BELIEVE you can or cannot do what is asked. Please note that the questions ask not what you should do but what you BELIEVE you can do

I believe I can…	No, I am sure I cannot[1]	No , I don't think I can[2]	I am not sure[3]	Yes, I think I can[4]	Yes, I am sure I can[5]
31. …plan my meals and snacks according to dietary guidelines.	☐	☐	☐	☐	☐
32. …check my blood glucose at least 2 times a day.	☐	☐	☐	☐	☐
33. …perform the prescribed number of daily insulin injections.	☐	☐	☐	☐	☐
34. …adjust my insulin for exercise, traveling, or celebrations.	☐	☐	☐	☐	☐
35. …adjust my insulin when I am sick.	☐	☐	☐	☐	☐
36. …detect *high* levels of blood sugar in time to correct.	☐	☐	☐	☐	☐
37. …detect *low* levels of blood sugar in time to correct.	☐	☐	☐	☐	☐
38. …treat a *high* blood sugar correctly.	☐	☐	☐	☐	☐

39. …treat a *low* blood sugar correctly.	☐	☐	☐	☐	☐
I believe I can…	No, I am sure I cannot[1]	No , I don't think I can[2]	I am not sure[3]	Yes, I think I can[4]	Yes, I am sure I can[5]
40. …keep daily records of my blood sugars.	☐	☐	☐	☐	☐
41. ...decide when it's necessary to contact my doctor or diabetes educator.	☐	☐	☐	☐	☐
42. ...ask my doctor questions about my treatment plan.	☐	☐	☐	☐	☐
43. ...keep my blood sugars in the normal range when under stress.	☐	☐	☐	☐	☐
44. ...check my feet for sores or blisters daily every day.	☐	☐	☐	☐	☐
45. ...ask my friends or relatives for help with my diabetes	☐	☐	☐	☐	☐
46. ...inform colleagues/others of my diabetes, if needed.	☐	☐	☐	☐	☐
47. ...keep my medical appointments.	☐	☐	☐	☐	☐
48. ...exercise 2 to 3 times weekly.	☐	☐	☐	☐	☐
49. …figure out what foods to eat when I am dining out.	☐	☐	☐	☐	☐
50. …read and hear about diabetes complications without getting discouraged	☐	☐	☐	☐	☐
51. …manage my diabetes well overall.	☐	☐	☐	☐	☐

SECTION 4 – Your mood

Some of the questions in this section ask about your mood and psychological wellbeing. We know people with type 1 diabetes have higher rates of depression before attending self-management courses, but we don't know if it also prevents people from attending these courses.

52. Do you take medication for depression?

Yes[2](go to Q63) ☐
I used to, but not now[1] ☐
No, I never have[0] ☐

53. Have you had any other treatment for depression (e.g. counselling/therapy)?

Yes[2] (go to Q63) ☐
I used to, but not now[1] ☐
No, I never have[0] ☐

The next 2 questions screen for depression.
Over the past **2 weeks**, how often have you been bothered by any of the following problems

(Chose one option for each problem from 0-3)?	0 Not at all	1 Several days	2 More than half the days	3 Nearly every day
54. Little interest or pleasure in doing things	☐	☐	☐	☐
55. Feeling down, depressed or hopeless	☐	☐	☐	☐

Add up your score (0-3) for question 54 & 55:

- *If you scored 2 or less, please go to Q63*
- *If you scored more than 2, please continue to Q56*

Because you scored **more than 2** on the screening questions we would like to ask some more questions about your mood. If your answers indicate that you are at higher risk of depression, where clinically indicated, we will contact you and your GP to let you know. If you would not like us to contact you and your GP about this then either do not complete this section, or tick the box below.

☐

I would not like me or my GP to be contacted regarding my likelihood of depression

Over the **last 2 weeks**, how often have you been bothered by any of the following problems? (If you have been unwell in the past 2 weeks, think back to the last time you were well).

(Chose one option for each problem from 0-3)	Not at all[0]	Several days[1]	More than half the days[2]	Nearly every day[3]
56. Trouble falling or staying asleep, or sleeping too much?	☐	☐	☐	☐
57. Feeling tired or having little energy?	☐	☐	☐	☐
58. Poor appetite or over-eating?	☐	☐	☐	☐
59. Feeling bad about yourself, that you are a failure or have let yourself or your family down?	☐	☐	☐	☐
60. Trouble concentrating on things, such as reading the newspaper or watching TV?	☐	☐	☐	☐
61. Moving or speaking so slowly that other people could have noticed? Or the opposite, being so fidgety or restless that you have been moving around a lot more than usual?	☐	☐	☐	☐

62. Thoughts that you would be better off dead or of hurting yourself in some way?	☐	☐	☐	☐

SECTION 5 – Emotional distress

Living with diabetes can cause anxiety and distress. These may come and go depending on other aspects of your life: finances, health, relationships etc. We want to assess how much of an emotional burden your diabetes is to you at the moment, but also what your level of confidence is in dealing with it on a daily basis.

Which of the following diabetes problems are currently an issue for you?

(Tick the box that gives the best answer for you)	Not a problem 0	Minor problem 1	Moderate problem 2	Somewhat serious problem 3	Serious problem 4
63. Feeling scared when you think about living with diabetes?	☐	☐	☐	☐	☐
64. Feeling depressed when you think about living with diabetes?	☐	☐	☐	☐	☐
65. Worrying about the future and the possibility of serious complications?	☐	☐	☐	☐	☐
66. Feeling that diabetes is taking up too much of your mental and physical energy every day?	☐	☐	☐	☐	☐
67. Coping with complications of diabetes?	☐	☐	☐	☐	☐

SECTION 6 – Quality of life

This section includes four questions about your daily life. Chronic illness can affect the quality of your life in different ways. Some people don't feel that it has any effect. Others may feel that it interferes with their life a lot.

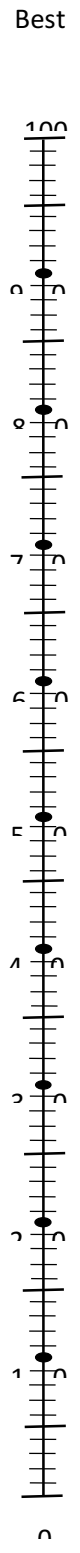
Read the four statements below and tick in the relevant box according to **how much** you feel your health has interfered with each statement over the **past 4 weeks**.

How much has your health interfered with your…?	Not at all[0]	Slightly[1]	Moderately[2]	Quite a bit[3]	Almost totally[4]
68. …normal social activities with family, friends, neighbours or groups?	☐	☐	☐	☐	☐
69. …hobbies or recreational activities?	☐	☐	☐	☐	☐
70. …household chores?	☐	☐	☐	☐	☐
71. …errands and shopping?	☐	☐	☐	☐	☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is **today**, in your opinion. *Draw a line from the box below to whichever point on the scale indicates how good or bad your health state is today.*

Your own health state



SECTION 7 – About you and your Diabetes

We would like to know a bit more about you and your diabetes control and treatment. In this section we ask you about your insulin treatment, your follow-up appointments and any complications you have related to diabetes.

72. Gender

Male[1] ☐ **Female**[2] ☐

73. Ethnic origin

White[1] ☐ Black[2] ☐ Asian[3] ☐ Chinese[4] ☐ Mixed[5] ☐ Other[6] ☐ *Please specify*

74. Where you born in the UK?

No[1] ☐ Yes[2] ☐

75. Are you currently?

Married or co-habiting[1] ☐ Divorced or Separated[2] ☐ Widowed[3] ☐ Single[4] ☐

76. Do you have any dependents (children under 16 years or in full time education)?

No[1] ☐ Yes[2] ☐

77. Do you have any complications related to diabetes? (*tick all that applies to you*)

Kidney problems[1] ☐
Foot problems[2] ☐
Nerve damage[3] ☐
Eye problems[4] ☐
Stroke[5] ☐
Heart disease[6] (e.g. heart attack, heart failure, angina, other) ☐

78. We would like to know about your use of our different diabetes services.

For each healthcare professional tell us how many times you have SEEN them and made CONTACT (e.g. telephone/email) in the last 12 months.

	Please state number of VISITS[i]	***Please state number of CONTACTS[ii]***
Diabetes nurse in hospital[a]		
Diabetes nurse in community[b]		
Dietitian in hospital[c]		
Clinical psychologist/Psychiatrist[d]		
Diabetes doctor in hospital[e]		
Diabetes doctor in community[f]		
GP[g]		
Practice nurse[h]		

79. How many times in the past 12 months **have you** missed **a diabetes appointment (with a doctor, nurse, dietitian or psychologist).**

(*Please state number of missed appointments at each place*)

In the hospital[a]	**In the community[b]**

80. In the last 12 months **how many times have you been** admitted to hospital **with a diabetes related problem (e.g. hypoglycaemia or foot ulcer)?**

State number of admissions

81. In the past 12 months **how many days have you been unwell as a result of diabetes, this includes any time spent in hospital, as well as time off sick from work or unable to continue your day to day routine.**

State number of days

82. What medication do you take for your diabetes?

Insulin name *e.g. Novorapid*	Dose *(number of units*)	Time taken *e.g. lunch*

83. Do you know your most recent glycated haemoglobin (HbA1c) test result?

I am not familiar with this test[0] ☐
No, I don't know my result[1] ☐
Yes[2] ☐
(Specify result)……

84. Have you had any hypoglycaemia, of any severity (i.e. self-detected and self-treated to very severe requiring hospital attention) in the last 12 months?

No[1] (go to page 21) ☐
Yes[2] ☐

85. Do you know when your 'hypos' are commencing?

(Please mark on the scale where your awareness of onset of hypoglycaemia lies)

Never aware 1	2	3	4	5	6	Always aware 7
☐	☐	☐	☐	☐	☐	☐

Thank you for completing this survey. Your responses are invaluable to us.

If you do not have type 1 diabetes; thanks for showing interest in this study. There are many research studies taking place at King's college London that may suit you. Please contact the research team to discuss.

Next steps:

- Please return this survey to us in the envelope provided.
- Once we have received it we will give you your gift voucher.
- We will either give your gift voucher to you at your next hospital appointment, send it in the post or email it to you. We will use the address you have provided at the start of the survey.
- Allow up to 6 weeks for your gift voucher to arrive.

The research team will be publishing their findings over the next couple of years.
Identifiable information will be anonymised.
If you are interested in seeing what we have found please visit www.hin-southlondon.org or www.clahrc-southlondon.nihr.ac.uk

Best wishes,

Dr Sophie Harris

Dr Sophie Harris
The BUDiE Study
Diabetes Research team
King's College London
Weston Education centre
10 Cutcombe Road
London SE5 9RJ

tel: 0207 848 5670
email: kch-tr.BUDiE@nhs.net

www.budie.org

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19.1.21 Appendix H: Sample C (HCP) survey

Healthcare Provider Questionnaire (please tick one response for each question):

1. Do you look after people with type 1 diabetes?
    a. Yes
    b. No *(go to number 20)*

2. How many adults with type 1 diabetes do you provide care for each year?
    a. <10
    b. 11-50
    c. 51-100
    d. 101-200
    e. >201

3. Please score below how important you think self-management is for your type 1 diabetic patients?

    0 ----------1 ----------2 ----------3 ---------- 4----------5
    Not at all important very important

4. Please score below how effective you feel current structured education programmes are at facilitating patient self-management?

    0 ----------1 ----------2 ----------3 ---------- 4----------5
    Not at all effective very effective

5. Whose responsibility do you think it is to ensure people attend structured education***? Here, you can choose more than one option.***
    a. Diabetes doctors
    b. Diabetes nurse specialist
    c. Dietitian
    d. General practitioner
    e. Patient
    f. Other (please state)……..

6. Below are nine statements about diabetes. They ask for your general opinion. Please consider each statement and mark in the box where your opinion lies.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
People with type 1 diabetes are capable of self-managment					
The important decisions regarding daily diabetes care should be made by the person with diabetes.					
Healthcare professionals should help people with diabetes make informed choices about their care plans.					
Almost everyone with diabetes should do whatever it takes to keep their blood sugar close to normal.					

The emotional effects of diabetes are pretty small					
Tight control is too much work.					
What the patient does has more effect on the outcome of diabetes care than anything a health professional does.					
People with diabetes have a right to decide how hard they will work to control their blood sugar					
People with diabetes have the right not to take good care of their diabetes					

7. Have you ever observed a DAFNE course?
    a. Yes
    b. No

8. Do you currently teach on a DAFNE course?
    a. Yes
    b. No

9. Imagine you have 10 of your usual type 1 diabetes patients, how many of these would fall into the following groups: (write the number of patients out of ten)
    a. Completed structured education (DAFNE or similar)?.....
    b. Referred and waiting to attend structured education?.....
    c. Referred but did not attend or did not complete the course?.....
    d. Offered referral but declined?.....
    e. Never been offered?.....

10. Only 30% of type 1 diabetics in Southwark and Lambeth have completed a DAFNE course. Please give up to **THREE** reason that you think this is?
    ……
    ……
    ……
    ……..

11. Considering your patients who have **never** been referred/attended DAFNE or similar please give **up to five** reasons why you think this is. Please rank these in order of importance to you. 1 being the major factor preventing referral/attendance for the majority of patients.
    ……
    ……
    ……
    ……
    ……
    ……
    ……..

12. How often do you have the opportunity to discuss complicated diabetes patients with a multi-disciplinary team?

a. Daily
b. Weekly
c. Monthly
d. Quarterly
e. Annually
f. Never

12. Please read the four statements below and mark in the box that best fits your clinical practice.

	Never	Rarely	Sometimes	Usually	Always
How confident are you that you can identify patients with low health literacy i.e. patients with little background knowledge of health?					
How often do you consider a person's literacy skills when advising a therapy?					

13. Have you ever been taught specific communication skills for use in 'difficult consultations' e.g. motivational interviewing/attended communication skills workshop etc.
    a. Yes
    b. No

14. How do you think we can improve attendance at structured education? Please give up to **THREE** ideas
    ……
    ……
    ……
    ……
    ……
    ……
    ……

16. Where is your main place of work?
    a. Intermediate care
    b. Primary care
    c. Secondary care
    d. Tertiary care

17. What is your job title?
    a. Consultant Physician
    b. Diabetes nurse specialist
    c. Specialist Registrar
    d. Dietitian
    e. General practitioner
    f. Clinical Psychologist
    g. Other (please specify)

18. For how many **years** have you been working in diabetes?
    a. <5 years
    b. 5-10 years
    c. 10-15 years
    d. >15

19. Please mark any of the following additional diabetes qualifications you have?
    a. Warwick certificate in diabetes
    b. ENB Diabetes 928

c. Post-graduate certificate
d. Post-graduate Diploma in Diabetes
e. MSc
f. Other (please name) ……

20. You have completed the questionnaire.

Thank you very much for giving up your time to fill in this questionnaire.
The research team will be carrying out interviews and focus groups to further discuss the issues raised by the project. We may invite you to participate.

19.1.22 Appendix I: Topic guides

19.1.22.1 Interview Topic Guide

Research question: **Experiences of self-management courses including barriers to attendance/engagement**

Introduce yourself & project

Background

- Information about participant
    - Tell me about when you were first diagnosed with diabetes, what happened?
- How does diabetes impact on your daily life?
- Thinking about your diabetes now, how do you manage it day to day?
    - What are the easy/second-nature bits to do? What do you find more difficult/annoying? And why?
- What are the most useful things you learnt in managing your diabetes? How did you learn these?

Self-management

- When people talk about self-management or self-care what does it mean to you?
- [prompts – SMBG, feet, clinic, exercise, dose-adjusting]
- Do you regularly check your blood sugar? Do you reflect on the readings? Do you adjust your insulin dose? What gives you the confidence to adjust doses?
- How has your ability or will to self-care changed over time?
- [prompts – dealing with diagnosis, transition period, parental input, life events]
- Do you find you manage your diabetes differently in different circumstances, for example at home versus work? Why?
- Does anything else affect your self-management?
- Most people have ups and downs in managing their diabetes. Thinking back to when you were first diagnosed to today, would you say this is the case for you? When?
- How do you motivate yourself to manage your diabetes day to day?
- Have you ever attended a self-care course?

DAFNE

- Describe DAFNE
    - Has this ever been discussed with you? Tell me more
    - [Prompts – How/who/perceived benefit/motivated them to go]
    - We will discuss some things that might put people off DAFNE, but before we do that what do you think has/would put you off going so far?
- Groups:
    - How do you feel about learning in groups with other people with type 1?

    - Would you feel more comfortable in certain groups?
    - Positives and negatives?
    - Anything else put you off a group?
    - What would encourage you to join?
- Length:
    - People suggest that the length of the course makes it difficult for them to attend – what do you think?
    - Ideal length? Concentrated/spread-out? Why?
- Numeracy & "Education":
    - Diabetes management can involve doing some maths for carbohydrate counting and working out insulin doses. Does this put you off?
    - Some people get put off by the term 'education' as it reminds them of school– would that put you off? What do you think it should be called?
- How would your work/home commitments affect you attending a course?
- Anything else preventing attendance?
- Potential improvements to facilitate attendance?

Information sources

- There are so many ways to get information and advice about your diabetes - Where do you go for information or advice about your diabetes?
- Do you feel that you can get helpful advice easily?
- What ways do you find best to learn about managing your diabetes?
- How do you think the different sources that you use influence your decision making?
- Is there anything else that you think helps you make decisions about the best way to manage your diabetes?

Networks:

- Are you in contact with any other people with diabetes?
    - Method of communication [blogs,forums,clinics]
    - Positives & negatives
    - Influence attendance at DAFNE

Technology:

- Some people use smart-meters, bolus calculators and apps to support their diabetes management. Do you use anything like that?
    - Tell me more

Close

- Do you feel that we have missed anything out that you would like to add?
- Thank you

19.1.22.2 BUDiE Study Focus Group Topic Guide

1. Introduce group
2. Introduce study and outline results
3. Do these results surprise you?
4. Blue sky thinking – if we didn't have the current DAFNE structure but just the principles/curriculum, how would it look?
    a. Length of time
    b. Time offered
    c. Who attends
    d. Location
    e. Who delivers it
    f. How is it delivered
5. How important is the peer support aspect of DAFNE and similar courses?
6. A lot of people have asked for online content, but we know that meeting peers is one of the benefits of DAFNE. Is there an alternative strategy?
    a. Social media
    b. Peer support groups – local/virtual
    c. Buddying system
7. Some people have commented that they would prefer shorter chunks outside of working hours. Do you think this is feasible?
    a. Commissioning/Financing
    b. HCP working out of hours/planning (flexibility)
    c. Keeping motivation
    d. enabling peer support
8. How can we change the message people are given?
    a. People who have done DAFNE often say that they were sold a carb counting course, but it is much more.
    b. Others say their healthcare professional didn't promote it as much as they should have done
9. Another thing that has come up in interviews has been the varying degree of abilities. Some people saying that they already have a lot of knowledge, through to some walking out of DAFNE because the concepts were too complicated. How can we cater for this? (On this spectrum of ability/knowledge, which group is more important/in need?

10. The focus group shows lots of potential ways to improve access to structured education. Which do you think is the most important? (Why? Feasible? Timescale/Cost, how would you do it?)

19.1.22.3 BUDiE Study Focus Group

19.1.22.3.1 Online Resource Topic Guide

1. Introduce study, outline results & reason for focus group
2. How often do you use the internet to help you manage your diabetes?
3. What sort of things would you look up online?
    - Do you often find what you are looking for?
    - Is it an easy process?
    - How do you know what to trust?
4. What about social media?
    - Do you regularly use it?
    - Would you use it for your diabetes?
    - What do you like or dislike about it?
5. In an ideal world how would the internet help you manage your diabetes?
6. Would you visit a webpage that signposted you to other tried and tested resources? How would you design this? What would you expect to find there? Do you know or use anything like this already? Who would be involved in designing this? Would it be national or local? Would you expect peer resource/recommendation on it? How would you search within it? Self-referral capability e.g. DAFNE/foot clinic?
    - If you were packing for holiday and weren't sure what you needed to do with your needles and insulin for security check, where would you find out more?
    - If you were having trouble with hypos after exercise, where would you go for advice about this? Could you use the internet for this?
7. Do you think having more information online would encourage you to learn more about your diabetes? Do you think it might help you manage your diabetes/come to DAFNE?
8. A lot of people talk about the importance of peer support, do you think you can get that virtually?
9. Is there anything that you would like from an online directory?
10. Thanks & next steps
    - Patient reference group to build directory
    - Online carb counting module

19.1.23 Appendix J: Number of people allocated to each calendar year in P1, at a ratio of 1 attender to 3.6 non-attenders.

Year	Number in DAFNE group	Number in Non-DAFNE group	Total
<2006	83	0	**83**
2006	26	91	**117**
2007	48	175	**223**
2008	46	169	**215**
2009	30	109	**139**
2010	26	95	**121**
2011	28	102	**130**
2012	17	62	**79**
Total	**304**	**803**	**1107**

19.1.24 Appendix K: P1 Subset analysis of cases with missing data compared to the study database population and compared to cohort used in sensitivity analysis.

Categorical variable with missing data (n = unknown)		**Excluded as more than one missing variable (n=152)**	**Included in the model**	
			Data present	Data unknown
HbA1c at time of intervention (n=364) (n = 247 in model)	Age (IQR)	33 (16.75) p < 0.001	40 (18) p<0.001	32 (16)
	Gender (%male)	55.7% p = 0.911	56.77% P = 0.760	57.89%
	Ethnicity (%white)	72.8% p = 0.884	72% p = 0.910	71.6%
IMD score (n = 108) (n in model = 39)	Age (IQR)	40 (20) p = 0.017	37.3 (18.6) p = 0.021	48 (23)
	Gender (%male)	54.6% p = 0.761	57.2% p = 0.678	53.8%
	Ethnicity (%white)	57.4% p = 0.007	73.8% p <0.001	28.2%
Hospital admission 2 years prior to intervention (n= 423) (n in model = 294)	Age (IQR)	40 (18) p = 0.004	37 (18.68) p <0.001	41 (18.1)
	Gender (%male)	52.0% p = 0.035	58.1% p = 0.337	54.8%
	Ethnicity (%white)	93.9% p < 0.001	61.2% p <0.001	95.9%

Appendix L: P1 Sensitivity analysis of binary regression analysis with exclusion of cases with more than one missing variable.

This model predicted 77.4% of cases, with goodness of fit Chi ^{2} 6.29 p=0.614 and Nagelkerke R square 0.175.

Characteristics (comparator)	**Attendance at DAFNE (n = 955) OR (95% CI)**	***p* value**
Age (years)	0.978 (0.963, 0.994)	0.006
Gender (female)	0.729 (0.525, 1.011)	0.058
Ethnicity (non-white)	0.487 (0.317, 0.747)	0.001
IMD score		
- **<25%**[a]		0.001
- **25-50%**	0.526 (0.334, 0.828)	0.006
- **50-75%**	0.541 (0.347, 0.843)	0.007
- **>75%**	0.507 (0.322, 0.801)	0.004
HbA1c at time of intervention (DCCT%)		
- **<7.5%**[b]		<0.001
- **7.5-8.9%**	1.702 (1.088, 2.662)	0.02
- **>9%**	1.927 (1.218, 3.05)	0.005
Diabetes-related admission 2 years prior to intervention	1.722 (0.654, 4.532)	0.271
Duration of diabetes at time of intervention (years)	0.991 (0.974, 1.008)	0.301

19.1.25 Appendix M: P2 correlation coefficients

Variable	SNS	HL	Education attainment (3 categories)
SNS			
Correlation coefficient	1	0.3	0.42
P value	-	<0.001	<0.001
N	486	484	481
HL			
Correlation coefficient	0.3	1	0.24
P value	<0.001	-	<0.001
N	484	487	481
Educational attainment			
Correlation coefficient	0.42	0.24	1
P value	<0.001	<0.001	-
N	481	481	486

Table of results for Spearman rank test of correlation between numeracy (SNS), health literacy (HL) and 3 categories of educational attainment. Correlation of >0.4 is taken as significant.

Variable	English language	Ethnicity	Born in UK
English language			
Correlation coefficient	1	0.2	-0.65
P value	-	<0.001	<0.001
N	496	480	478
Ethnicity			
Correlation coefficient	0.2	1	-0.27
P value	<0.001	-	<0.001
N	480	480	477
Born in UK			
Correlation coefficient	-0.65	-0.27	1
P value	<0.001	<0.001	-
N	478	477	478

Table of results for Spearman rank test of correlation between English language ability, ethnicity and Born in the UK. Correlation of >0.4 is taken as significant.

19.1.26 Appendix N: P2 sensitivity analysis

Forward Wald of attendance v non-attendance with missing cases removed:
Cases included 367 (74%)
Significant variables were:
HCP message (ref: positive) OR 0.36, 95%CI 0.20 – 0.65, p= 0.001
Educational attainment (university vs primary school) OR 0.51, 95% CI 0.30 – 0.87 p= 0.013
HbA1c knowledge and result (Hba1c <7.5% vs 7.5-9%) OR1.68, 95% CI 0.95 – 3.0 p= 0.076
Gender (male): OR 0.54, 95% CI 0.34 – 0.85, p= 0.008
13-17% variance explained with the four variables (Cox & Snell R^2 0.13 and Nagelkerke R^2 0.176)
Goodness of fit with Hosmer and Lemeshow: Chi^2 6.93, p= 0.54

Further sensitivity analysis by doing **Backward Wald analysis**:
Cases included 427 (86%)
This produced the same significant variables:
Gender OR 0.56 95% CI 0.36–0.86 p=0.009
HCP message OR 2.75, 95% CI 1.51–5.0, p=0.001
HbA1c knowledge p=0.004
Educational attainment p=0.008